DOCUMENT RESUME

ED 336 926 EC 300 658

AUTHOR	Taylor, Steven J.; And Others
TITLE	A Policy Analysis of Private Community Living Arrangements in Connecticut.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	Connecticut State Dept. of Mental Retardation, Hartford.
PUB DATE	Jul 88
NOTE	116p.
AVAILABLE FROM	Syracuse University, Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340 ($5.20).
PUB TYPE	Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	Costs; Deinstitutionalization (of Disabled); *Group Homes; Independent Living; Individual Differences; Individualized Programs; *Mental Retardation; *Normalization (Handicapped); *Private Sector; Program Evaluation; Supervision
IDENTIFIERS	*Connecticut

ABSTRACT

This report, one of series of reports describing innovative practices in integrating people with disabilities into community life, presents the findings of a study of privately operated community living arrangements funded by the Connecticut Department of Mental Retardation. It addresses three questions: (1) are the costs of the most expensive privately operated community living arrangements justifiable? (2) do people living in privately operated community living arrangements receive more or less supervision than they require? and (3) does the design of privately operated community living arrangements allow for sufficient flexibility to meet the needs of people with mental retardation. Major conclusions are that the costs of these programs are justifiable and comparable to those of public programs, that most living arrangements provide more supervision than their clients require, and that private community living facilities have lacked flexibility and individualization. Appendixes present the evaluation methodology and two article reprints, "Common Issues in Family Care" (Steven Taylor and Julie Ann Racino) and "Supporting Adults with Disabilities in Individualized Ways in the Community" (Julie Ann Racino). Includes 11 references. (DB)

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A POLICY ANALYSIS OF PRIVATE COMMUNITY LIVING ARRANGEMENTS IN CONNECTICUT

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A POLICY ANALYSIS OF PRIVATE COMMUNITY LIVING ARRANGEMENTS IN CONNECTICUT

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July, 1988

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I: Evaluation Methodology

II: Article: Supporting Adults in Individualized Ways in the Community

III: Article: Common Issues in Family Care

Introduction

This report contains the findings and recommendations of a study of privately operated community living arrangements funded by the Connecticut Department of Mental Retardation (DMR) conducted between December, 1987 and June, 1988. The study was directed towards three questions selected by DMR:

1. Are the costs of the most expensive privately operated community living arrangements justifiable?
2. Do people living in privately operated community living arrangements receive more or less supervision than they require?
3. Does the design of privately operated community living arrangement allow for sufficient flexibility to meet the needs of people with mental retardation?

The report is divided into three major sections: Background Information; Findings; and Recommendations. The Appendices include a description of the study methodology, and resource information.

BACKGROUND INFORMATION

While this study focused on privately operated community living arrangements, it is important to understand these community alternatives in the context of the mental retardation service system in Connecticut. The Department of Mental Retardation is organized into six regions, in addition to Mansfield and Southbury Training Schools, operating under the direction of Central Office. DMR operates directly or contracts with private providers for a broad range of services, including residential services, family support services, case management, resource services, and child and adult day services.

Connecticut's residential service system is comprised of a variety of publicly and privately operated facilities and settings:

*Mansfield and Southbury Training Schools. As of January, 1988, the combined populations of Mansfield and Southbury, the state's two large institutions, stood at approximately 1559. Mansfield and Southbury contain both ICF/MR (Medicaid-funded "Intermediate Care Facilities for the Mentally Retarded") and non-ICF/MR units. State plans call for decreases in the populations of both Mansfield and Southbury.

*Regional Centers. DMR operates ten regional centers administered by the regional offices with a combined population of approximately 559 as of January, 1988.

*Private Institutions. These include residential schools, long

term care facilities, and nurseries, with a combined population of approximately 905 in 1987.

*DMR operated "Community ICFs/MR." DMR operates 39 "Community ICFs/MR," with a total population of 321 as of February, 1988.

*Privately operated "Community ICFs/MR." DMR contracts with private providers to operate 27 "Community ICFs/MR," with a total population of approximately 143 as of February, 1988.

*Community Training Homes. DMR licenses "community training homes," or foster or family care homes, serving approximately 135 children and youth and 349 adults. While the community training home program traditionally has been a DMR operated program, DMR plans to contract with private providers to operate their own community training home programs.

*DMR operated Community Living Arrangements. DMR operates a small number of non-ICF/MR community residences.

*DMR "Assisted" Apartments. DMR regions operate "assisted living arrangements," which are unlicensed and provide less than 24 hour supervision. These arrangements are variously referred to as "monitored apartments," "supervised apartments," "staffed apartments," "subsidized apartments," or "community apartments."

*Private Community Living Arrangements. DMR contracts with private providers to operate community living arrangements for 1238 people as of February, 1988. There are approximately 217 privately operated community living arrangements, ranging in size from one to 15 people.

This study was designed to examine privately operated community living arrangements.

FINDINGS

COSTS OF THE MOST EXPENSIVE COMMUNITY LIVING ARRANGEMENTS

This section of the report looks at the costs of privately operated community living arrangements funded by DMR: the reasonableness of the costs and how community living arrangements are funded.

The purpose of this section is not to present a cost-benefit analysis of community living arrangements. While the study involved site visits to private programs, we did not attempt to evaluate the quality of life or programmatic effectiveness of community living arrangements in light of costs. The study was addressed to whether DMR's funding of community living arrangements is reasonable and justifiable.

It is noteworthy, however, that a study by Conroy & Feinstein Associates conducted under contract with DMR concluded that CARC v. Thorne class members who have moved from congregate settings into the community, including privately operated arrangements, are significantly better off than they were previously (Conroy, Feinstein, & Lemanowicz, 1988). Conroy, Feinstein, & Lemanowicz (1988) report:

> This is our conclusion about deinstitutionalization under the CARC v. Thorne consent agreement: the people who have moved from institutional to community placements have benefited (sic)

immensely in almost every way we know how to measure. Community placement should continue, and, assuming mechanisms and resources are adequate, it should accelerate, because people are clearly better off in Connecticut community living than they are in Connecticut institutions (p. 77).

Before presenting the findings of this study regarding the costs of private community living arrangements, a few words of explanation on the funding of private programs should be given. Private providers operating community living arrangements are reimbursed through separate rates from the Department of Income Maintenance (DIM) and the Department of Mental Retardation. The DIM rate is intended to pay for room and board costs, while the DMR rate is intended to pay for service costs. DMR service rates have been paid according to five levels of care, with a maximum per diem or "cap" for each level. Since 1986 (Fiscal Year 1987), the Commissioner of DMR has approved "overcap requests" submitted by regional offices to reimburse agencies in an amount beyond the cap for Level V care (the regulations authorize the Commissioner of the Department of Income Maintenance to grant an exemption to the per diem rate for Level V upon the written request of the Commissioner of Mental Retardation). For the purposes of this study, the "most expensive community living arrangements" are operationally defined in terms of community living arrangements with "overcap" budgets. As of February, 1988, 183 out of a total population of 1238 people were living in private community living arrangements funded at a rate exceeding the cap for Level 5. TABLE I contains a breakdown of DMR overcap budgets, listing per diems (DMR rate only), the number of clients funded at each rate, and

the annual DMR cost.

TABLE I.

DEPARTMENT OF MENTAL RETARDATION
PER DIEMS FOR MOST EXPENSIVE
PRIVATE COMMUNITY LIVING
ARRANGEMENTS ("OVERCAPS")

February 1988

DMR Per Diem	Number of Clients	DMR Annual Cost
$ 91 - 150	49	$ 2,295,397
$151 - 250	66	4,186,714
$201 - 250	35	2,710,942
$251 - 300	14	1,405,501
$301 - 350	18	2,086,799
$351 - Over	1	178,850
TOTAL	183	$12,864,203

*For children's homes, DMR costs include both service and room and board amounts.

As noted below, DMR has revised its rate-setting system effective June 30, 1988.

Finding 1. The average costs of the most expensive private community living arrangements are comparable with the costs of public institutions in Connecticut.

Cost comparisons of institutions versus community programs are complex and notoriously unreliable. First of all, all programs have hidden costs, costs that do not appear in program budgets. For example, institutional budgets may not include capital and depreciation costs; community program budgets may not include the costs of generic community services. Second, in order to be valid, a cost comparison must be based on comparable populations; that is,

costs must be compared for people with the same level of needs. A common failing of many cost studies of institutions versus community programs is that they compare the costs of serving people with mild disabilities with those with severe disabilities. Third, a cost comparison should compare programs providing the same level of service. It is meaningless to compare the costs of a richly staffed program, whether in an institution or the community, with a poorly staffed one.

A comparison of institutional and private community living arrangements is made here to provide a rough indicator of the reasonableness of costs of private community living arrangements. Budget information on Connecticut institutions and community living arrangements were obtained from DMR and undoubtedly do not account for many hidden costs. No systematic data were collected on the level of disability of people living in institutions or community programs or on the intensity of services offered in the state's regional centers and training schools as opposed to private community living arrangements. We assume that many of the people remaining in institutions have severe and multiple disabilities. However, our observations of community living arrangements and our interviews with private providers and regional staff lead us to believe that many people served in the community in the most expensive community living arrangements are also among those with the most severe disabilities, including severe and profound mental retardation, multiple disabilities, medical involvements, and "challenging behavior."

Based on data provided by DMR on the costs of different settings

as of February, 1988, the average costs of the most expensive private community living arrangements are in line with the average costs of institutions in Connecticut. TABLE II compares the average per diems (per person per day cost) for public institutions and the most expensive private community living arrangements. The TABLE includes: (1) the per diem for Mansfield Training School; the per diem for ICF/MR certified units at Mansfield; the per diem for Southbury Training School; the per diem for ICF/MR certified units at Southbury; the per diem for DMR's regional centers; and the per diem for the most expensive ("overcap") community living arrangements, including both DMR and DIM rates and an estimated day program per diem of $37.

TABLE II.

COMPARISON OF AVERAGE PER DIEMS OF THE MOST EXPENSIVE PRIVATE COMMUNITY LIVING ARRANGEMENTS WITH INSTITUTIONS

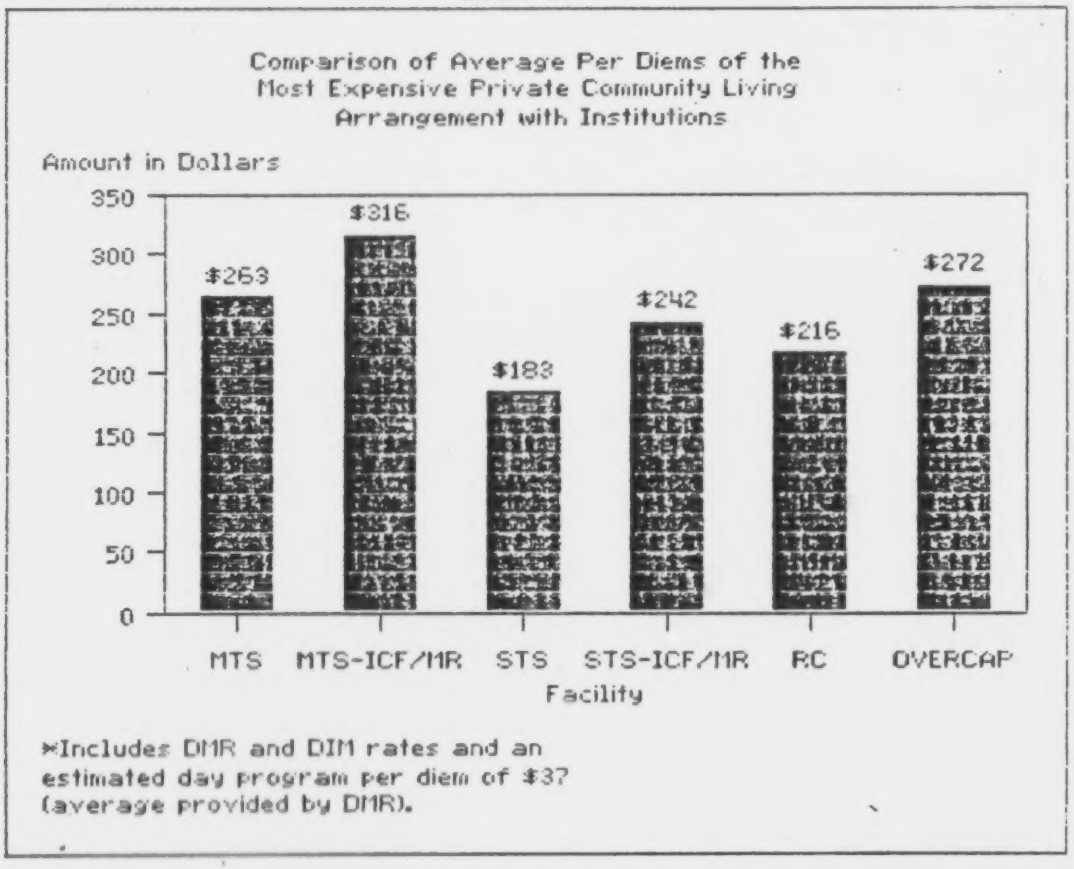
February 1988

Mansfield Training School	$263
Mansfield Training School - ICF/MR	$316
Southbury Training School	$183
Southbury Training School - ICF/MR	$242
Regional Centers	$216
Most Expensive ("Overcap") Private Community Living Arrangements	$272

*Includes DMR and DIM rates and an estimated day program per diem of $37 (average provided by DMR).

CHART I (on the next page) provides a graphic depiction of the figures contained in TABLE II.

CHART I.



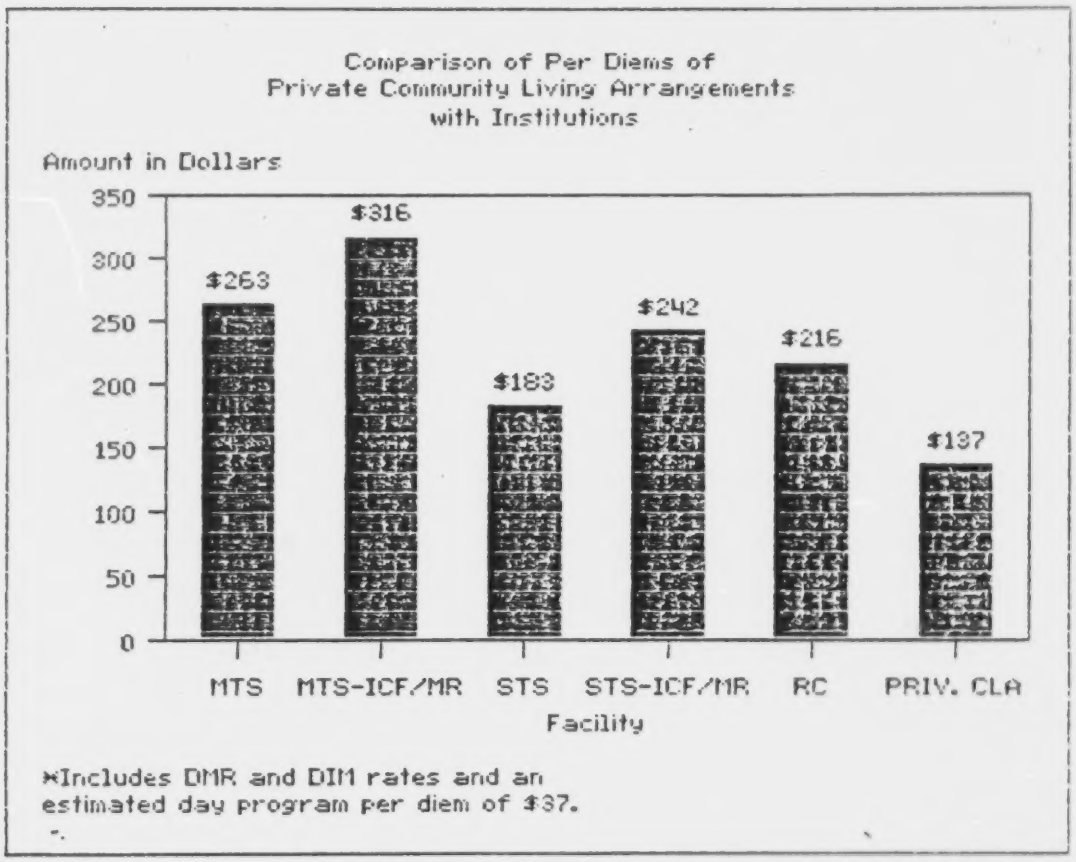
*Includes DMR and DMH rates and an estimated day program per diem of $37 (average provided by DMR).

As indicated in TABLE I, the per diem for the most expensive private community living arrangements, $272, is comparable to Mansfield's per diem, less than ICF/MR units at Mansfield, and slightly higher than the per diems for the regional centers, Southbury, and ICF/MR units at Southbury. With the decline in the populations of Southbury and Mansfield in accord with consent decree projections, the per diems at these institutions are expected to increase to $335 at Mansfield and $239 at Southbury, even if total expenses remain constant.

It should be noted that an evaluation of the costs of a system of community services should not be based on the costs of the most expensive programs. A failure to examine statewide averages would paint a misleading picture of funding issues. As indicated by Conroy and Bradley (1985), it is not unusual for community programs to show a wide range in cost. In their study of the Pennhurst deinstitutionalization, the costs of community programs ranged from $19.64 to $252.66 in 1981-82. Conroy and Bradley (1985) and Ashbaugh and Allard (1984) also report that institutional per diems conceal a wide variation in the costs of units within individual institutions.

The average costs of private community living arrangements in Connecticut are significantly lower than the most expensive facilities and than Mansfield, Southbury, and the regional centers. The per diem for private community living arrangements, including "overcap" programs, is $137.36 (DMR and DIM rates and an estimated $37 for day programs). TABLE III and CHART II present a comparison of this figure with institutional per diems in Connecticut.

CHART II.


Comparison of Per Diems of
Private Community Living Arrangements
with Institutions
Amount in Dollars
350
300
250
200
150
100
50
0
$263
$316
$183
$242
$216
$137
MTS
MTS-ICF/MR
STS
STS-ICF/MR
RC
PRIV. CLA
Facility
*Includes DMR and DIM rates and an
estimated day program per diem of $37.

While this report focuses specifically on the costs of private community living arrangements in Connecticut, it is relevant to point out that compared to other states Connecticut historically has had high mental retardation expenditures, especially for institutions. Spending for private community living arrangements must be interpreted in the context of trends in spending for mental retardation services in general.

TABLE III.

COMPARISON OF PER DIEMS OF PRIVATE COMMUNITY LIVING ARRANGEMENTS WITH INSTITUTIONS

1988

Mansfield Training School	$263
Mansfield Training School - ICF/MR	$316
Southbury Training School	$183
Southbury Training School - ICF/MR	$242
Regional Centers	$216
Private Community Living Arrangements ("Overcap" ("Overcap" and "Nonovercap")*	$137

*Includes DMR and DIM rates and an estimated day program per diem of $37.

Citing national studies reporting data collected from 1977 to 1986, TABLE IV compares mental retardation/developmental disability spending in Connecticut with other states. TABLE IV compares mental retardation/developmental disability in Connecticut with other states according to: spending per capita, based on the total state population (total, institutional, and community); spending as a

TABLE IV.

COMPARISON OF MENTAL RETARDATION/DEVELOPMENTAL DISABILITY EXPENDITURES IN CONNECTICUT WITH OTHER STATES

Comparison	Year	Connecticut Figures	National Average	Connecticut's Rank	States With Higher Expenditures
MR/DD Spending Per Capita (Total State Population)[1]	1986	$81.91	$38.04	2	North Dakota
MR/DD Institutional Spending Per Capita (Total State Population)[1]	1986	$52.18	$19.49	1	None
MR/DD Community Spending Per Capita (Total State Population)[1]	1986	$29.73	$18.55	9	North Dakota, District of Columbia, New York, Minnesota, Rhode Island, New Hampshire, Maine, Michigan
MR/DD Spending as a Share of Personal Income[1]	1986	———	———	3	North Dakota, Minnesota
MR/DD Institutional Spending as a Share of Personal Income[1]	1986	———	———	2	North Dakota
MR/DD Community Spending as a Share of Personal Income[1]	1986	———	———	16	North Dakota, Minnesota, New York, Rhode Island, District of Columbia, Maine, Vermont, Pennsylvania, New Hampshire, Louisiana, Montana, Michigan, Wisconsin, Ohio, Nebraska
MR/DD Institutional Per Diems[1]	1986	$198.94	$126.79	2	Alaska
Rate of Increase in MR/DD Institutional Per Diems[1]	1977-1986	400.28%	184.67%	6	North Dakota, New Hampshire, Nevada, Massachusetts, District of Columbia

TABLE IV. continued

Comparison	Year	Connecticut Figures	National Average	Connecticut's Rank	States With Higher Expenditures
ICF/MR Costs Per Resident[2]	1985	$45,358 (Per Diem: $124.27)	$32,960 (Per Diem: $90.30)	5	Alaska, Massachusetts, New York, Vermont

Sources:
[1]Braddock, Hemp, & Fujiura, 1986
[2]Lakin, Hill, White, & Wright, 1987

share of personal income within a state (total, institutional, and community); institutional per diems; rate of increase in institutional per diems from 1977 to 1986; and ICF/MR costs per resident.

The consistent pattern that emerges from this TABLE is that Connecticut has ranked at the top of the states in terms of mental retardation/developmental disability spending, with spending for institutions accounting for its rank. As indicated in TABLE IV, Connecticut ranked first in institutional spending per capita, second in institutional spending as a share of state personal income, second in institutional per diems, sixth in the rate of increase in institutional per diems from 1977 to 1986, and fifth in ICF/MR costs per resident (as of 1986, 68.9% of ICF/MR funding in Connecticut went to public institutions).

As of 1986, Connecticut ranked significantly lower in community spending than in institutional spending, although it remained above the national average in this category also. In per capita spending in the community, Connecticut ranked ninth, while in community spending as a share of personal income, Connecticut ranked sixteenth. Perhaps this disparity in institutional versus community spending accounts for Connecticut's subaverage deinstitutionalization rate in the late 1970s and early 1980s. According to Braddock, Hemp, and Fujiura, in the period 1977 to 1986, the populations of public institutions in Connecticut declined 25.44% compared to a national average of 32.68%. Connecticut ranked thirtieth among the states during this period. National data comparing Connecticut with other states in terms of community

spending and rate of deinstitutionalization are not available since DMR began approving "overcap requests" to fund private community living arrangements.

Although many factors probably account for Connecticut's relatively high mental retardation expenditures, the economic climate within the state is undoubtedly a major one. As a state, Connecticut has a high cost of living and low unemployment rate. TABLE V (on the next page) summarizes key economic indicators for the State of Connecticut.

As indicated in this TABLE, Connecticut has a per capita income (personal income divided by state population) significantly higher than the national average, $19,600 versus $14,641 in 1986. As of February, 1988, Connecticut had a statewide unemployment rate of 3.6%, a figure that placed it third lowest in the country after Hawaii and New Hampshire. The unemployment rate within five metropolitan areas in Connecticut ranged from 2.4% to 4.8%. Stanford's unemployment rate of 2.4% was the lowest unemployment rate of any metropolitan area in the country. In February, 1988, Connecticut had the eighth highest average weekly earnings of production workers on manufacturing payrolls among the states. In short, because of Connecticut's favorable economic picture, the costs of mental retardation services would be expected to be high compared to other states.

FINDING 2. The costs of the most expensive private community living arrangements are justifiable given the historical model of service adopted in Connecticut.

Under current DMR regulations, private community living

TABLE V.

COMPARISON OF CONNECTICUT WITH
OTHER STATES ON SELECTED ECONOMIC FACTORS

PER CAPITA PERSONAL INCOME

Connecticut (1986): $19,600

National Average: 14,641

Source: Connecticut Department of Labor, 1988

UNEMPLOYMENT RATE

Connecticut (1988): $3.6%

Range in Connecticut Metropolitan areas (1988):

Stanford (2.4%); Hartford (3.2%);
New Haven - Meridan (3.4%);
Bridgeport - Milford (4.4%); Waterbury (4.8%)

National Rate: 5.6%

State with Lower Unemployment Rate:

New Hampshire (3.1%); Hawaii (3.3%)

Source: U.S. Department of Labor, 1988

AVERAGE WEEKLY EARNINGS (PRODUCTION WORKERS ON MANUFACTURING PAYROLLS)

Connecticut (1988): $445.95

Connecticut's Rank: 8th Highest

Source: U.S. Department of Labor, 1988

arrangements are agency operated, licensed, and staffed facilities. The regulations contain minimum staffing requirements for each of five levels of care. According to the regulations, level of care II, III, IV, and V facilities must meet certain staffing ratios for each of three shifts. For level V facilities, which include the most expensive community living arrangements, the minimum required staff on duty are: 1st shift 1:3 residents; 2nd shift 1:2.5 residents; 3rd shift awake 1:6 residents. What is more important than the specific staffing requirements is the expectation that private community living arrangements will be staffed by three shifts of direct care staff, with awake night staff for facilities serving people with more severe disabilities. DMR licensing regulations are currently under revision and draft regulations have been prepared.

The major factor contributing to the costs of private living arrangements, including the most and least expensive, is staffing. For this study, we analyzed two separate sets of cost information on approved agency budgets: the first was a comparison of average cost centers of undercap and overcap private community living arrangements calculated by DMR; the second was a review of 29 "overcap" agency budgets (37 "overcap" budgets were provided by DMR; eight were excluded from analysis because of incomplete information; of those budgets that were dated, the dates ranged from December 1986 to November, 1987). Both sets of information break down agency budgets by four major categories contained on a DMR budget summary sheet: (1) salary and wages for administrative staff; (2) salary and wages for support staff (generally

professionals and consultants); (3) salary and wages for direct care staff; and (4) direct service costs for the individual residential program (a miscellaneous category including auditing, accounting, licensing, staff education and training, transportation, postage, telephone, advertisement, insurance, and "other"). The summary sheet also lists room and board costs, but since these are part of the DIM rate and not the DMR service rate, these costs were not analyzed. As noted later in this report, DMR's cost reporting system is also under revision.

Before reporting on our analysis, a few words about the nature of the budget information provided by agencies should be offered. Agencies varied widely in terms of the types of costs they reported. Some agencies charged a general management fee as a percentage of total program costs under the category for individual residential program, while others did not. Similarly, agencies differed in how they reported costs, especially under the categories for administrative staff and support staff. Several budgets listed administrative costs as a percentage, while most contained a breakdown of staff salary and benefits. One budget listed two behavioral specialists under the administrative category. The category of direct care staff appeared relatively consistent across agency budgets and, hence, comparisons based on this category are probably the most reliable.

Based on DMR's calculations and our own analysis, <u>costs for direct care staff account for between 70.4% and 72% of the budgets of the most expensive private community living arrangements and costs for total staff, including administrative, support, and</u>

direct care, account for between 86.4% and 86.5% of the budgets. TABLE VI provides a comparison of average annual costs per bed for "overcap" and "non-overcap" private community living arrangements by major cost category based on DMR's calculations.

TABLE VI.

COMPARISON OF COST CATEGORIES OF AVERAGE ANNUAL COSTS OF "OVERCAP" AND "NON-OVERCAP" PRIVATE COMMUNITY LIVING ARRANGEMENTS BY "BED"

	NON-OVERCAP		OVERCAP	
COST CATEGORIES	COSTS	PERCENTAGE OF COSTS	COSTS	PERCENTAGE OF COSTS
Administrative Staff	$2,948	12.9%	$4,332	6.7%
Support Staff	$1,942	8.5%	$5,081	7.8%
Direct Care Staff	$15,221	66.4%	$46,904	72%
Individual Residential Program	$2,816	12.3%	$8,787	13.5%
TOTAL	$22,927	100%	$65,104	100%

Source: DMR
Percentages Rounded

As indicated in TABLE VI, the annual average for non-overcap programs are $22,927, while the average for overcap programs are $65,104. Costs are greater for overcap programs for each of the four categories. However, direct care staff accounts for most of the difference between the two budgets. Costs for direct care staff

are 75.1% of the difference between overcap and non-overcap budgets, and total staff costs are 82.6% of the difference.

TABLE VII summarizes data from the analysis of the budgets of 29 of the most expensive private community living arrangements.

As summarized in this TABLE, the budgets of the most expensive private community living arrangements vary greatly from each other. Per diems range from $123.74 to $490 (this was a one-person program whose per diem has apparently declined since the original budget was prepared), with an average of $193.86. The range of costs for each major cost category are as follows: (1) administrative staff: 0-23.3%; (2) support staff: .3%-25.1%; (3) direct care staff: 37.2%-80.4%; and (4) individual residential program: 2.8%-28.1%. Only one program devoted less than 50% of its budget to direct care staff, at 37.2%. However, this budget also had the highest percentage devoted to support staff, 25.1%, supporting the conclusion that support staff were playing direct care staff roles. On the average, the 29 programs allocated 70.4% of their budgets to direct care staff and 86.4% of their budgets to direct, support, and administrative staff.

Apart from several budgets that contained relatively high management fees (and these budgets typically had low administrative costs), the only consistently high cost item under the individual residential program category contained in the 29 budgets was transportation. Each budget contained a major transportation line ranging from $3,000 to $16,740. DMR's figures indicate that transportation is the largest single cost item under the individual residential program category for overcap programs at $2,934 per bed (33.4% of that category and 4.5% of the total costs). Private

TABLE VII.

COMPARISON OF COST CATEGORIES OF AVERAGE COSTS OF MOST EXPENSIVE PRIVATE COMMUNITY LIVING ARRANGEMENTS

Size of Facilities:

One-Person: 2

Two-Person: 1

Three-Person: 17

Four-Person: 5

Six-Person: 3

Unknown: 1

Total Budget: $6,234,998

Per Diem:

Average	Range
$193.86	$123.74 - $490

Percentage of Budget by Major Cost Category:

	Average	Range
Administrative Staff	7.8%	0(1.9)% - 23.3%
Support Staff	8.2%	0(.3)% - 25.1%
Direct Care Staff	70.4%	37.2% - 80.4%
Individual Residential Program	13.6%	2.8% - 28.1%

Source: 29 Agency Budgets

community living arrangements, or at least the most expensive ones, apparently routinely purchase or lease their own vehicles, rather than using other means of transportation.

A review of available data, including DMR figures, the budgets of private community living arrangements, interviews with regional staff and private providers, and observations of programs, yields some insights into the costs of the most expensive community living arrangements. As a general conclusion, the costs of the most expensive community living arrangements vis-a-vis other private community living arrangements appear to be explained by the complex interplay of severity of disability of people served in these programs, the size of the facilities (i.e., in smaller settings, there is generally more staff time available to residents), staffing patterns, and the trend toward "parity" in salary and wages of private agency staff with public agency staff. No single factor taken in isolation appears sufficient to account for the costs of the most expensive programs.

Severity of Disability. People living in the most expensive private community living arrangements appear to be significantly more disabled than those living in other facilities. While the "RET" ("Regional Eligibility Team") process used to determine levels of care should not be accepted as reliable, it is safe to assume that people classified as "Level V" are in general more severely disabled and have more intensive needs than those classified at lower levels. According to DMR's statistics, the most expensive ("overcap") private community living arrangements serve the vast majority of people classified at the upper end of the five levels of

care. Out of 225 people living in a level IV/V or V facility, 151 or 67% reside in facilities whose budgets are "overcap."

It would be misleading to imply that people with more severe disabilities cost more to support in the community under any and all circumstances. The costs of serving people with severe disabilities will depend on how they are served and the degree to which their needs are met. Connecticut's Community Training Home Program ("specialized family care") currently serves a number of adults and children with the most severe disabilities at a cost significantly lower than any other residential alternative and, in fact, at a lower cost than public or private community living arrangements for people with mild and moderate disabilities. However, not all people with severe disabilities can or should be supported in this way.

As part of our site visits to three DMR regions, we asked regional officials to explain the reasons for the costs of the most expensive private community living arrangements or, in other words, to justify each of their "overcap requests." Severity of disability was by far the most frequently offered reason for the costs of the most expensive programs. Out of 31 "overcap requests" reviewed with regional staff, this was the major reason mentioned in 23 cases. Each of these cases involved people with "behavioral" or "medical" complications. Some of the most expensive facilities are operated by out-of-state providers specifically recruited for their experience with people with the most severe disabilities. Similarly, in phone interviews with four regional directors, severity of disability was consistently mentioned as one of the primary factors contributing to high costs.

Size. Even a cursory review of DMR statistics reveals that among the most expensive private community living arrangements, smaller facilities have higher per diems than larger ones. According to DMR figures on per diems by size of facility, the cost increases as size decreases. The following is a breakdown of the per diems of the most expensive ("overcap") private community living arrangements by size:

Number of beds	Number of people total	DMR Per diem
1	2	$341.16
2	8	$264.58
3	81	$258.78
4	36	$232.60
6	24	$184.36

According to three out of four regional directors interviewed, small size is a major factor contributing to the costs of the most expensive programs.

While smaller settings have higher per diems than larger ones, this is not to suggest that the costs of one-, two-, or three-person settings are not reasonable or justifiable. People living in the smaller settings may have more severe disabilities than those in the larger ones. In other words, if six-person facilities served the same people living in three-person facilities, their per diems would rise due to increase staffing costs. According to several regional officials interviewed, smaller settings have been selected for people with the most severe disabilities, especially those with

"challenging behavior." For example, one man whose placement is one of the most costly in the state lives in a one-person setting. He has a history of abusing himself and attacking staff and other residents while he was living at Mansfield and a four-person ICF/MR. By all accounts, since being placed in a one-person setting, his abusive behavior has declined significantly. The provider has recorded detailed data to show a dramatic decline in the frequency and intensity of negative behaviors. Over time, the plan is to find at least one compatible roommate to share the home with him, thus markedly decreasing costs and still maintaining the significant gains he has made.

Since most of the cost differentials between smaller and larger settings are accounted for by staffing costs, the smaller settings have more staff time available to meet the needs of residents. In their longitudinal study of Pennhurst, Conroy and Bradley (1985), a major cost advantage of smaller community programs over the institution was the increased level of effort expended on behalf of clients. In other words, community programs showed a greater cost advantage when measured in terms of cost per hour of staff time than cost per client day. If staff are actively involved with clients, as opposed to merely watching over them, the size of facilities can only be increased at the expense of the intensity of staff intervention.

Staffing Patterns. As noted above, DMR's current licensing regulations for private community living arrangements mandate rigid staffing ratios and require awake night staff for people with more intensive needs. Providers can request a waiver of staffing ratios

and the requirement for awake night staff, but this does not appear to have been done for any "overcap" facilities. Although the regulations do not require shift-staffing, the vast majority of the most expensive private community living arrangements employ this staffing model. Of the 29 "overcap" budgets reviewed, each provided for shift staff.

The use of shift staff, with awake staff on the night shift, contributes to the costs of the most expensive community living arrangements. While the staff ratios on some shifts might be justified in terms of contact with clients, as indicated above, it is difficult to justify the universal use of awake night staff. Extremely few people need awake staff at night and for those who do, this should be justified individually. Our visits to community living arrangements in Connecticut lead us to question whether the majority require awake night staff.

Awake night shift staffing drives up the costs of small facilities in particular. Since staff do not ordinarily interact with clients during the night and are available only for emergencies, or in some instances, to assist with routine care such as lifting, clients do not accrue benefits from a richer staffing ratio at night in a small versus a large facility. In most instances, one staff member can just as easily monitor a six-person facility as a three-person facility at night. Even if all other costs are identical, the operation of two three-person facilities will result in costs for one additional staff person at night over one six-bed facility.

Our visits to community living arrangements also raise questions

about the need for professionals to provide direct care at some facilities. In at least some cases, it appears that professionals, especially licensed or registered nurses, are providing routine care that trained nonprofessionals could provide. For example, at one facility that served people with severe physical disabilities who did not appear to need skilled medical care on a routine basis, a nurse was assigned to each shift. In fact, a nonprofessional was the substitute staff person for a nurse on one shift. According to DMR officials, nursing requirements for medication administration contribute to this reliance on professional nursing staff.

The Trend towards "Parity." A major trend in Connecticut is towards parity between the salaries of private agency staff and state employees. DMR's FY 87 annualized budget includes two salary adjustments authorized by Governor O'Neill that total $6,783,402. All staff employed by private providers currently under contract with the Department of Mental Retardation for day and residential services who currently earn salaries less than $45,000 per year were eligible for the increase.

Although this trend will eventually increase the costs of all private community living arrangements in Connecticut, it appears to have impacted most heavily on recently negotiated "overcap" budgets. The increase in private agency staff salaries was the second most often cited reason for "overcap" requests by regional staff. According to DMR regional staff, private agency salaries anywhere near the state entry level salary automatically places an agency budget at "overcap." DMR central office officials state that it is the number of staff not the salaries of staff that contribute

to "overcap" situations. DMR regional staff also explained that one major provider currently "eats" (pays for from its own sources) the salaries and benefits for staff working at "nonovercap" "Level V" facilities.

In addition to the trend towards parity, it should be recalled that Connecticut has a high cost of living and one of the lowest unemployment rates in the nation. Public and private providers will continue to find it necessary to pay high salaries relative to other states to attract staff. Hence, the costs of services may be expected to rise.

It is relevant to point out that in the Pennhurst study, Conroy and Bradley (1985) noted that most of the cost differential between the institution and community programs was attributable to the differences in the state as opposed to private agencies salaries and fringe benefits: "Clearly if, either as a by product of growth and maturation of the community services network or as a matter of policy, community program salaries and fringe benefits increase, the cost advantage of community programs will shrink considerably" (p. 241.

While the discussion under this finding has focused narrowly on the per diems of individual facilities, a full understanding of the funding of the most expensive community living arrangements in Connecticut requires a broader view. The costs of some of the most expensive private community living arrangements can be explained not in terms of current individual facilities but in terms of other factors. For example, some of the highest per diems are found at providers that recently entered the state and that plan to expand

their services. As these providers develop new programs, administrative costs charged to individual budgets probably will decrease. Similarly, some of the small facilities with high per diems expect to increase the number of clients and spread costs across one to three additional people.

In assessing the costs of the most expensive private community living arrangements, it is important to note that DMR regional staff can provide detailed rationales for "overcap requests" and appear to make reasonable judgments on budgets, within the current model of service. During interviews, regional staff appeared extremely knowledgeable about individual agency budgets and offered sound reasons for approving budgets submitted by private agencies.

FINDING 3. DMR has taken positive steps to revise its rate-setting system for private community living arrangements and has replaced the inadequate and out-moded Level of Care system.

In addressing the costs of private community living arrangements in Connecticut, it is relevant to look at how private providers are funded to operate community living arrangements.

DMR, together with DIM, has undertaken a major revision of the rate reimbursement system for private community living arrangements. As noted previously, private providers have been reimbursed with separate DIM (room and board) and DMR (service) rates. DMR's rate has been paid according to five levels of care, with a dollar figure ranging from $19.93 to $89.83 corresponding to each: I (supervised); II (semi-structured); III (structured); IV (intensive); and V (highly intensive). These levels were determined through a "regional eligibility team" (RET) process that assessed

clients along five dimensions. Beginning in Fiscal Year 1987, "overcap requests" were granted to reimburse private providers at a rate exceeding the "cap" ($89.83) for "Level V clients."

The Level of Care system was characterized by numerous flaws. First, the caps attached to each level were inadequate to cover the actual costs of services for many people. As one regional official explained, the service rates or caps were established at a time when the expectations regarding providers were significantly lower than they are today. Second, without waivers of the Level V caps during the last two years, it is doubtful whether many people with severe disabilities would have been provided the opportunity to live in the community. Third, the RET process used to determine rates was unreliable and resulted in inconsistent determinations of client levels. Finally, the level of care system was inflexible and obscured the individual needs of people in community living arrangements.

For the past several years, DMR and DIM have been undergoing a review of the rate reimbursement system for private community living arrangements. Based on this review, a new rate setting system has been developed that is designed to replace the level system with a more flexible "client-based" approach.

During the period from July 1, 1987 to June 30, 1988, three rate systems have been in effect in Connecticut. The first is the five-level rate system with caps that applies to most providers licensed prior to July, 1987. The second is an interim collapsed level system that replaces the five levels with three, "Assisted," "Supervised," and "Ongoing Comprehensive." The third is the new

"negotiated service rate system" that was implemented on a pilot basis in one region. As of July 1, 1988, the funding of all private community living arrangements will shift to the new negotiated service rate system.

Under the new system, DMR's regional offices have responsibility for negotiating individual rates with private providers within regional resource allocations. As part of the rate-setting process, each provider must file an Operational Plan and an Audited Consolidated Operation Report, a detailed statement of costs for the preceding year. According to draft regulations, "Analyses of the Operation Plan, ACOR, and other relevant information relating to management, financial and programmatic performance will be used in the rate negotiation process." The Operating Manual for Parent Organizations Providing Residential and Day Programs to Individuals with Mental Retardation states that the DMR Central Office will provide the regional offices with "reasonable ranges of costs" with which they can compare the costs of providers in specified cost categories. The Operating Manual describes the cost center for negotiations with private providers as the community living arrangement or facility rather than the individual. Recent information provided by DMR's Central Office in a phone interview indicated that the cost centers under the new system actually will be the provider. This is expected to give providers the flexibility to shift resources from one of their facilities to another. The rate-setting system is not designed to be based on the individual "OPS" or "Overall Plan of Service."

For the coming fiscal year, regional resource allocations will

be based on the current provider operating costs plus an inflation factor and salary adjustments, in addition to a per diem of $155.80 for "expansion beds." Theoretically at least, regional office officials will be able to negotiate rates flexibly for existing and new community living arrangements within this regional allocation.

According to DMR's Central Office, the new negotiated rate-setting system abolishes all levels (although some Central Office staff refer to "guidelines" for three levels) and will provide regional offices and providers with the flexibility to design services around individual needs within the available resources. However, many regional officials and private providers do not share this understanding and believe that rates will correspond to the three levels, "Assisted," "Supervised," and "Ongoing Comprehensive." In short, there is a gap between how Central Office understands the new system and how many others understand it.

DMR's five year plan, Planning for the Future 1988-92, leaves the impression that the level of care system will be replaced by a three-level category of service reimbursement system:

> Providers will no longer be licensed to provide a specific level of care but will be staffed and paid for the level of support or service each resident requires as defined by three categories of out-of-home living arrangements:
>
> Assisted - for persons who require some assistance to maintain a living arrangement but who do not require the supervision of a staff person overnight
>
> Supervised - for persons who require overnight support and supervision by trained staff person through the night and at

other times

Ongoing Comprehensive Support - for persons who because of severe, multiple, and chronic disabilities, require intensive supervision, a specially adapted environment, and a combination of professional support services for the forseeable future.

The Operating Manual for the new rate system similarly contains a flow chart depicting these three levels of service.

Interviews with regional staff revealed that at least some believe that rates will be set based on three "guidelines" or "caps." Describing the new system, one regional director stated, "It is probably not all that different than the level of care." A regional staff person who serves as a liaison with private providers said, "If the regulations are passed, there will be three new levels of assisted, supervised, and ongoing comprehensive with caps." A third regional staff member gave this explanation of the new system: "It is unknown what dollar amounts will be assigned to the three levels. Artificial caps will be given." A fourth regional official speculated that the three level system is designed to be a transition step between the five-level system and an individualized rate-setting system. Finally, regarding rate-setting for private providers, a fifth regional official commented, "We expect to be using the three-level system by July 1."

While the negotiated rate-setting system has the potential to introduce greater flexibility in the funding of private community living arrangements, a failure to clarify the relationship between rates, on the one hand, and the three categories, Assisted,

Supervised, and Ongoing Comprehensive, on the other, could undermine the intent of the new system. The intent of the central office DMR was to use the three levels as a framework for discussion of the supervision needs of people. This framework might also lend itself to presenting the anticipated average costs of community living arrangements under the new negotiated rate system.

SUPERVISION

This section of the report focuses on the level of supervision provided in private community living arrangements and specifically addresses the question of whether people living in these settings receive more or less supervision than they require.

FINDING 4. DMR's current licensure regulations (now in the process of revision) encourage over-supervision of people living in private community living arrangements by requiring 24-hour supervision at most facilities.

DMR's current regulations for the licensure of private community living arrangements (Licensure of Private Facilities as Group Homes, Community Living Arrangements, Group Residences, Residential Schools, and Habilitative Nursing Facilities for Mentally Retarded and Autistic Persons, April 17, 1984) require 24-hour supervision for all but people with the mildest disabilities. As noted previously, under the current licensure regulations, private community living arrangements are licensed and reimbursed according to five levels of care, with I ("supervised") the lowest and V ("highly intensive") the highest. The regulations contain rigid staffing ratios for each of three shifts for Levels II through V. The lowest staff-to-client ratio is 1:6.

Since a very small number of private community living arrangements are licensed as Level of Care I, the overwhelming number of facilities are required to provide 24-hour supervision.

According to a listing of private community living arrangements dated February, 1988, four facilities with 18 funded beds were licensed as Level I.

As with other regulatory requirements, private providers can request a waiver of the requirement for 24-hour supervision. The burden is placed on the provider to justify why 24-hour supervision should not be provided. By all accounts, relatively few waivers of 24-hour supervision have been requested or granted. No statewide data on waivers is readily available.

DMR is undergoing a revision of the licensure regulations. Recent drafts appropriately eliminate requirements for staff supervision. According to Central Office staff, staffing patterns and supervision requirements will be addressed in the contracts negotiated with providers.

FINDING 5. DMR's current licensure regulations (now in the process of revision) encourage over-supervision in private community living arrangements by requiring awake night shift staff at most facilities.

The current regulations require awake night staff at community living arrangements licensed for Levels of care III through V. In view of the fact that only 20 facilities with 121 funded beds are licensed as Level I or Level II, the majority of private community living arrangements are required to provide awake night staff.

Like the requirement for 24-hour supervision, providers can request a waiver of this requirement and this appears to be one of the most common licensure waivers requested and granted. According to one provider, a waiver of awake night staff could be obtained if

the provider clearly documented that incidents do not occur at night and that clinical change had occurred in the person. Most private community living arrangements appear to provide awake night supervision through shift staff, although some have been successful in obtaining waivers.

By requiring awake night staff in private community living arrangements, DMR's current regulations treats as routine what should be treated as exceptional. Whether viewed in terms of the additional cost involved in paying staff to be awake during the night or in terms of overprotectiveness and restrictiveness, the assignment of awake night staff to a community living arrangement should be regarded as an exceptional step requiring individual justification.

DMR's draft regulations do not require awake night staff.

FINDING 6. The licensure requirements and funding of private community living arrangements encourages providers to provide more supervision than some people require.

Under DMR's current and proposed draft regulations, a private community living arrangement is an agency-operated and state-licensed facility. Funding through the current 606 account for private community living arrangements is tied to licensing and providers cannot be reimbursed for residential services provided in people's own homes (e.g., a rented apartment or owned house). One provider interviewed explained that he provided "drop-in" support to two people living in their own apartments at his own expense. One of these people strongly wanted her own apartment as opposed to living at a licensed facility in which her life would be

controlled. According to the provider, DMR regional staff had been supportive of his agency continuing to provide services to these people, but had been unable to secure funding to enable him to do so.

If and when people living in a private community living arrangement are found to require less supervision than provided there, they must either move from the facility and receive services and supports from another source (DMR apartment program) or stay at the facility and continue to receive the same level of supervision. As noted below, a sizeable number of people continue to live at private community living arrangements that provide more supervision than they require.

Operating as a disincentive for private providers to move people to other programs providing less supervision is what some DMR regional staff referred to as "backfilling." This is a term used to describe the "replacement" of a person who has moved from a facility. Since people being placed in community living arrangements today are significantly more disabled than most of those currently served in the community, a provider who moves a person from a facility is likely to have that person "replaced" by someone with more intensive needs. As one regional director explained,

> One agency in the region has moved people into condominiums. They then backfilled--I hate that word--with people who are really Level V. This is a disincentive to private providers because they end up with a tougher person; for example, someone who is medically involved or who beats up people or breaks

windows.

Another regional director commented, "The provider needs a financial incentive to move people on. . .if they are going to backfill with people with more severe disabilities." In short, a provider runs the risk of having a person who moves from a community living arrangement "replaced" by someone with greater needs, with no additional resources to serve that person. One regional director stated that budgets are not normally renegotiated during a contract year if one person is replaced by another. Under the new negotiated system while renegotiation is possible, several regional staff mentioned that they do not expect that such renegotiation would typically take place.

FINDING 7. A sizeable number of people (as reported by the private sector and regional staff) living in private community living arrangements appear to receive more supervision than they require.

Relying on the statements of regional staff and private providers, it is reasonable to assume that a significant number of people living in private community living arrangements receive more supervision than they require. In view of the regulatory requirements and incentives favoring over-supervision, this should not be surprising.

Each of four regional directors interviewed stated that at least some of the people in private community living arrangements could live in the community with less supervision or were ready to move on to "less restrictive settings." As one of these regional directors stated, he was not involved enough on a day-to-day basis to say

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whether there were many or a few people who fell into this category. One of the regional managers contrasted private community living arrangements with DMR apartments:

> For the state apartments it has worked fantastic to have people in their own homes. Before if one person needed 24 hours of supervision all would get it. We started to recognize that people needed freedom and didn't need all that supervision. We were able to increase the program without increasing the staff because people had grown with the program. We have done this to some extent with a few providers in the private sector but the system works against this.

In phone interviews with private providers, six out of 13 stated that they serve people who do not require the level of supervision provided in their living arrangements. The number of people cited by these six agencies ranged from one or two at a small agency to 18 to 20 at a larger one. Some of these providers explained that people who could live in the community with less support have no where else to go. One stated:

> People are oversupervised. We can't get funding for apartments and there's no place for them to go.

Other providers indicated that some people receive more supervision than they require because they happen to live in facilities with people who do need 24-hour supervision. According to one provider:

> People are ready to receive less than 24-hour supervision. There are people who don't need as much as others. A staff person is there to keep an eye on two or three more than the rest.

In addition to the people requiring less supervision mentioned by providers, many other people who live in 24-hour supervised facilities with awake night staff appear to be relatively independent. As one DMR case manager explained, "There are places where a person goes out in the community alone, but cannot remain in their home alone without a licensing waiver." A staff member in another DMR region said, "There's some places where staff are asked to leave by the people living there so staff ends up hanging out in the lobby to provide 24-hour supervision."

During the phone interviews and site visits, we were informed about many people living in 24-hour supervised facilities who function independently in the community for at least brief periods of time. In the phone interviews, almost every provider identified between two and 20 clients who regularly travelled alone in the community; for example, walked to work, went to the store, took walks, and used public transportation. At one agency, two people held competitive jobs and used public transportation yet lived at community living arrangements providing 24-hour supervision. In the site visits, we met some people who seemed to be capable and independent, but who received 24-hour supervision because of possible safety hazards; for example, the fear that a person would smoke in bed or use the stove.

FINDING 8. While DMR is taking positive steps to reduce the rigidity of the regulations for private community living arrangements regarding staff supervision, this may not dramatically reduce the level of supervision provided in most facilities without further direction and guidance from DMR.

In recognition of the rigid and inflexible nature of the current licensing regulations for private community living arrangements, DMR is undergoing a major revision of these regulations. Draft versions of the regulations eliminate the levels and staffing ratios contained in the current regulations.

While DMR's efforts to reduce the rigidity of the regulations are positive and will undoubtedly enable some providers to offer more individualized services, it cannot be assumed that a revision of the regulations in and of itself will have a major impact on the level of supervision provided in most community living arrangements. In the first place, many regional staff and private providers believe that most people living in private community living arrangements require the level of supervision specified in the regulations. While they may indicate that a number of people could get by with less supervision, they generally mean that these people do not fit into licensed community living arrangements and are ready to move to more independent living. The problem is defined not in terms of how community living arrangements are staffed, but in terms of who should be placed there. As one regional official commented, people currently classified as Levels IV and V need the staffing indicated in the current regulations. Another stated, "The level of supervision will be determined by the IDT team. It probably won't be that different than under the level system."

As illustrated by the current regulations, private community living arrangements have been organized under the assumption that 24-hour awake supervision should be provided unless otherwise

justified. In contrast, in many other states and service systems, 24-hour supervision, especially awake night supervision, must be justified based on the individual.

Perhaps because of the history of the private community living arrangements program, many providers and regional staff are, in the words of one regional official, "overprotective." One regional staff member explained why many independent people may require 24-hour supervision: "People use poor judgment and bring people home from town and are taken advantage of." A private provider had this to say about awake night staff: "We choose to have this in case of an emergency." Another private provider stated clients have to demonstrate that they are capable of living safely in order to be left alone. For a number of providers and regional staff, a vague possibility that a person may have a behavior episode or an accident justifies 24-hour awake supervision.

In the second place, without economic incentives, private providers will be reluctant to replace more independent people who do not require 24-hour supervision with people with more challenging needs. Since rates are set for facilities, rather than individuals, and since these rates usually will not be readjusted during the fiscal year, providers may continue to be penalized financially for accepting a person with severe disabilities in an existing community living arrangement.

In the third place, many people living in private community living arrangements will continue to require ongoing support. Since support is equated generally with shift staff, the level of supervision provided in most community living arrangements cannot be

expected to decrease significantly.

Due to the more restrictive Connecticut Department of Labor Laws and Regulations and the preferences of providers, people in private facilities are increasingly supported by shift staff. Of course, the current DMR licensure regulations also encourage shift staffing.

While the Federal Fair Labor Standards Act (FLSA) makes provisions for live-in staff, according to DMR's review of Connecticut labor laws and an interview with their wage enforcement agent, "Connecticut regulations mandate that any hours live-in staff are required to be on the premises of the workplace be counted as hours worked and subject to minimum wage." During our interviews and site visits, we often were told that these wage and hour standards made the use of live-in staff unfeasible. A regional director stated:

> There are not too many staff who sleep at night. They have shift staffing on all three shifts. Live-in staff are diminishing. It was too expensive with federal wage and hour to pay staff time and a half. They are electing to replace live-in by three shifts. It was too costly to recruit and pay at the new rate for live-in staff.

According to two regional staff, all providers in their region except one used shift staff and the one exception was in the process of changing from live-in to shift staff because of wage and hour requirements. Two providers stated that they were willing to consider live-in staff, but that wage and hour standards were a potential problem. One of these said, "We don't know how to classify staff and we can't pay them for 24 hours." However, one

provider indicated that it was actually easier to obtain live-in staff because of changes in wage and hour standards.

Although all Department of Labor wage and hour guidelines are subject to various interpretations, the status of live-in staff under the federal standards is clearer than many other staffing arrangements. Live-in staff, or "employees who reside on the employer's premises permanently or for an extended period of time," need not be paid for all of the time they are at a setting. For example, they do not need to be paid for eight hours of sleep time or for free time, even when they are on call. In addition, certain staff who provide "companionship services" to people in their own homes are exempt from wage and hour standards. Recent interpretations by the Federal Department of Labor impact most directly on agencies that use relief staff to substitute for live-in staff and modified shift staff. Because of inconsistencies in the interpretation of federal standards, the Department of Labor has placed a temporary moratorium on investigations of community residences in order to develop clearer guidance for providers and enforcement officials. (For updated information on FLSA, see National Association of Private Residential Resources, 1987, 1988). Since Connecticut's labor laws are more restrictive than the federal government, though, private providers must follow these more restrictive standards.

Quite apart from federal and state wage and labor standards, most providers in Connecticut express a preference for shift staff as opposed to live-in staff. Out of 22 providers interviewed about staffing on the phone or in person, three used live-in staff, two

were open to live-in staff but currently used shift staff, and the remainder had a strong preference for shift staff. The reasons in favor of shift staff and against live-in staff included staff "burn-out" and turnover, difficulty in recruiting live-in staff, inappropriateness for community living arrangements for adults, the non-professional status of live-in staff, and staff "ownership" of the living arrangements. Two of the providers that used live-in staff believed just as strongly in the advantages of this approach. One stated:

> I wouldn't do it any other way. It becomes their home and things get done right away. . .The staff gets a lot of support and a liberal vacation plan. We have no problem with burn-out.

For regulatory changes to have a major impact on the level of staffing in private community living arrangements, DMR will need to encourage and work with providers to develop alternatives to shift staffing and also work with the Connecticut Department of Labor to revise Connecticut labor laws that may contribute to unnecessary program costs and restrict flexibility. As long as providers use shift staff as a routine matter, many people will continue to receive more supervision than they require, especially at night, since shift staff are almost always awake or at least must be paid for being awake. The issue confronting DMR is not simply whether or not people may need some level of support, but how support can be provided in individualized and flexible ways. Examples of flexible ways of supporting people include live-in staff, "paid roommates," on-call staff, neighbor support, and electronic communications systems. This leads us to a consideration of the flexibility and individualization of private community living arrangements.

FLEXIBILITY AND INDIVIDUALIZATION

This section of the report examines the third and final study question addressed by the study; namely, the flexibility and individualization of private community living arrangements in Connecticut.

FINDING 9. DMR has taken many positive steps to increase the flexibility, individualization, and responsiveness of private community living arrangements.

Connecticut's community-based service system for people with mental retardation is a system in transition. As indicated earlier in this report, despite high state expenditures for mental retardation and developmental disability services, Connecticut lagged significantly behind other states in deinstitutionalization in the period from 1977 to 1986.

In the past three years, DMR has made impressive strides in the development of regional administrative structures and funding mechanisms to support community services in the areas of residential services, supported work, and family support services. As part of its efforts to develop community programs, DMR has taken numerous steps to increase the individualization of privately operated community living arrangements. The following steps are especially noteworthy.

The review and revision of licensure regulations for private community living arrangements. DMR has developed draft regulations

that would eliminate the rigid levels of care and inflexible staffing ratios contained in the current licensure regulations.

The development of a new rate-setting structure. In line with the revision of licensure regulations, DMR has developed a new negotiated rate reimbursement system for private agencies. While not truly individualized, this new rate setting system should afford private agencies more flexibility in meeting the individual needs of people in community living arrangements. The new rate-setting system also transfers responsibility to DMR regional offices for negotiating service rates, thus moving decision-making regarding services closer to the people served.

The creation of the Temporary Support Services Fund. The Temporary Support Services fund (032 account) is a fund to pay for time-limited services to maintain people in the community. This fund is an innovative approach to meeting unique and unanticipated circumstances. According to regional staff and providers, these funds have been used successfully to obtain additional staffing to respond to crises, to provide intensive support to people with challenging behavior, and to fund nursing care for people experiencing or recovering from acute medical conditions. As one regional manager stated "temporary services has saved countless placements." Some private providers reported that they have experienced delays in obtaining Temporary Support Services funding. In order to provide for timely funding, DMR recently proposed changes in Temporary Support Services to enable funds to be provided to providers through amendments to their existing contracts.

The development of smaller community living arrangements. DMR

has actively encouraged and supported the development of small, primarily three-person, private community living arrangements. In some cases, DMR has funded two- or even one-person community living arrangements in order to respond to the unique needs of individual people. Without question, these one- to three-person settings offer the potential of greater individualization than larger facilities.

FINDING 10. The DMR Housing Subsidy Program is an innovative approach to enable people with mental retardation to maintain their owned or rented homes in the community.

Beginning in 1983, DMR started to provide subsidies to assist people with mental retardation in meeting housing costs to live in their own homes. Like the federal Section 8 housing subsidy, the DMR subsidy pays the difference between 30% of a person's net income and the total housing and utility costs up to a specified maximum. Since in Connecticut, as in other states, the availability of Section 8 funds is severely limited, DMR's housing subsidy represents an innovative state funding mechanism to support people with mental retardation to live in their own homes. DMR recently drafted new regulations clarifying usage of the housing subsidy after a controversy surrounding the use of program funds in one region. As of late 1987, over 263 people were receiving housing subsidies.

The DMR housing subsidy offers tremendous potential in enabling people with mental retardation to live in typical homes and to lead typical lifestyles in the community. While the subsidy has been used widely to support the housing costs of people served through DMR's supervised apartment program (also referred to as monitored

apartments, among other names), it has not been available to people supported by private providers since private community living arrangements are licensed facilities, rather than homes leased or owned by people themselves. For this reason, the full potential of the housing subsidy program has not been tapped.

FINDING 11. The private community living arrangement program is currently a "facility-based" approach and this limits the flexibility and individualization of the program.

Despite DMR's efforts to introduce flexibility and individualization into the private community living arrangement program, the program represents a "facility-based" approach to serving people with mental retardation. The program revolves around the community living arrangement, or facility, rather than around individuals. This is not to suggest that DMR officials and staff and providers have not made attempts to address the individual needs of people with mental retardation. It is to say that the current operation of private community living arrangements circumscribes the flexibility and individualization of the program.

By "facility-based," we mean that the private community living arrangements program incorporates the following elements.

Licensing of facilities. Private community living arrangements are licensed facilities. When agencies own or operate residential programs, licensing is appropriate. However, by its nature, licensing tends to limit people's choices and options about where and with whom to live. One agency administrator informed us about one previous client of his agency who simply did not want to live in a licensed setting and turn over control of her life to the state or

the agency.

Agency owned or rented. Private community living arrangements are agency operated, owned or rented, facilities. Since providers own or rent the residential setting, they ultimately control who lives there. As O'Brien and Lyle (1986) point out, under this arrangement, "the person with a disability is a guest in someone else's home" (p. I-27).

Agency staffed. Private community living arrangements are staffed by people hired, paid, and supervised by the agency operating the facility. Staff are employed by and accountable to the agency, not the people receiving the services. The staff's relationship with people is defined by conditions of employment set between the agency and staff.

Staffing ratios based on the group, not the individual. Staffing ratios and level of supervision are based on the needs of the group of people living at the facility. As a general rule, people receive the level of supervision required by the person with the most intensive needs. As discussed earlier, this can result in over-supervision for some individuals. To the extent that an individual has more or less intensive needs than others at the facility, he or she may not "fit into the program."

Linkage of Housing and Support. In order to receive services from a private provider, people must live at the provider's facility. Providers can only be reimbursed for services if the person lives at the community living arrangement.

Core Funding Tied to the Facility, Not the Individual. At least under DMR's current rate-setting system for private community living

arrangements, funding is based on the facility and not the individual. According to DMR forms provided to us as part of the ACOR system, the cost center under the negotiated "client-based" rate structure is the community living arrangement. Recent information provided by DMR indicates that providers will be able to shift funds between different cost centers, but even under this scheme funding levels are set based on the facility. A negotiated budget can be said to be individualized only to the extent that a community living arrangement houses only one person. Yet since this funding would not automatically follow the person if he or she moved to his or her own home, it does not represent an individualized rate. To its credit, DMR has developed a funding mechanism for Temporary Support Services which may be tied to the individual and designed to address individual needs and circumstances.

Weak relationship between individual planning and funding. Under the current level of care rate structure, there is a weak relationship between individual planning, as represented by the "OPS" or "Overall Plan of Service," and funding of community living arrangements. The rate-setting system and OPS process have proceeded independently. The RET (Regional Eligibility Team) process determined Level of Care determined Staffing Ratios and Rate. The OPS addressed services within specified staffing ratios and funding levels. At the most, private providers could use the OPS to develop future budgets or to request "add-ons," such as the Temporary Support Service. The OPS is sometimes referred to as "pie in the sky." Under the negotiated "client-based" rate-setting system, the OPS and rate-setting structure also appear to be

independent processes. According to draft regulations, "Residential client needs assessments serve to establish basic staffing patterns used in the annual negotiation of this rate." A residential client needs assessment is defined as "documents which present a composite assessment of individual client needs for each community living arrangement to assist in establishing the basic staffing pattern required in the residence."

A "facility-based" approach can be contrasted with a "nonfacility-based," "individualized," or "person-centered" approach to supporting people with developmental disabilities in the community. FIGURE I summarizes key elements of an individualized approach to community support for people with developmental disabilities. APPENDIX II contains a reprint of an article elaborating on these elements.

The distinction we are making between "facility-based" and "nonfacility-based" is similar to the distinction O'Brien and Lyle (1986) make between a "Landlord Strategy" and "Housing Agent/Personal Support Strategy." As O'Brien and Lyle point out, although a Housing Agent/Personal Support Strategy would open the way to much more effective services, funding and regulatory barriers can stand in the way of adopting this approach. FIGURE II, adapted from O'Brien and Lyle (1986), contrasts the Landlord Strategy with a Housing Agent/Personal Support Strategy.

As indicated in FIGURES I and II, the central feature of a nonfacility-based or individualized approach is <u>the separation of housing and support</u>. A manual prepared by Options in Community Living, a community support agency in Madison, Wisconsin, describes

FIGURE I.

Key Elements in Individualized Supports
for People with Developmental Disabilities

1. A Change in Thinking - We need to shift from an approach that "fits people into programs" to an approach that starts with people first and designs the supports around the people.

2. Separation of Housing and Support Components - People must be able to receive the intensity and type of support they need wherever they may live.

3. Choice in Housing - People must have a choice of a variety of kinds of housing: duplex, apartment, condominium, flat, trailer, or house.

4. Choice of Location of the Home - People must be able to choose where they want to live, including the specific neighborhood.

5. Choice of Living Alone or With Others - People must have greater choice about whom they will live with or if they will live alone.

6. Home Ownership/Leasing - Adults generally should own or lease their own homes, either alone on in conjunction with other people. Only under specific circumstances should adults live in the home of another or in agency-owned housing.

7. Individualized Supports - Supports should be tailored to an individual person and will vary in kind, amount, frequency and duration from person to person.

8. Flexible Supports - Supports must be easily adjustable as the needs of people change over time.

9. Community Assessments - Development of supports must be based on "getting to know" the person in a variety of community environments.

10. Building on Natural Supports - Services must build on natural community supports, including relationships with neighbors, families, friends, and acquaintances, and "generic" community services and organizations.

11. Choice of Support Providers - People with disabilities need to have greater control over the hiring and firing of their own support workers.

FIGURE II.

CONTRASTING STRATEGIES IN
RESIDENTIAL SERVICES

LANDLORD STRATEGY

* An agency acquires and manages the building.
* Staff are employed by the agency.
* Housing is offered along with other services such as instruction, supervision, and personal assistance in a tightly connected package. It is usually not possible for a person to refuse services and retain tenancy.
* Usually the resident contributes only a small part to program costs from discretionary income. Most program costs are paid by a third party, who may bundle several funding sources together to make up a daily per-person rate.
* People often assume that different types of buildings match different levels of handicap. The most able people live in apartments. The least able live in congregate health care facilities. The people in between belong in group homes.
* People are "admitted" to a "bed" as "residents" or "clients" and receive "residential programming" or "active treatment". At the conclusion of their stay, they are "discharged" or "graduated" or "transferred to a more appropriate program."
* An agency, not the people in residence, holds the property's lease, mortgage or title and owns most of the furnishings.

HOUSING AGENT/PERSONAL
SUPPORT STRATEGY

* An agency provides people with the help needed to locate, rent, and sometimes own their own homes.
* People get only as much help as they need in negotiating and arranging payments, making necessary modifications, and acquiring furnishings.
* People have opportunities to learn what they need to know to enjoy their homes in safety.
* People whose physical abilities limit their ability to do things for themselves and people who have not yet learned what they need to manage safely have in-home assistance.
* The agency joins with other local groups to influence the local housing market to offer suitable housing.
* Money from programs for people with disabilities is directed toward two distinct purposes: personal support and housing subsidy. Housing subsidy supplements a person's own resources from wages, entitlements (such as SSI), and family resources. In some places, separate agencies or departments have been created which specialize either in housing or in personal support.
* Each person an agency assists could have a different set of personal supports and a different mix of funds paying the rent or mortgage. Indeed, the agency could easily offer personal support to people who live with their parents.

Reprinted from O'Brien and Lyle (1986).

why it is important to separate housing from support:

. . .one agency should not provide both housing and support services. While we often advise and assist clients in finding, renting, and furnishing their apartments, Options no longer becomes the leaseholder or the landlord for client apartments. We want our clients to feel both control over and responsibility for their own living spaces. We also believe that receiving Options' services should not affect where clients live; our clients have a greater choice of living situations and know that beginning, ending or changing their relationships with us will not put them under any pressure to move. This policy also frees us from the time-consuming responsibilities and sometimes conflicting relationships involved in being a landlord. (Johnson, 1986)

Under a nonfacility-based or individualized approach to community support, people should have access to a range of housing options. While housing should be separate from support services, an agency might assist people in locating housing, signing leases, negotiating with landlords, matching roommates, purchasing furniture and furnishings, arranging for architectural adaptations, and obtaining housing subsidies. Illustrated below are the major types of housing arrangements:

Own home. This includes housing owned or rented in the person's own name.

Parent's or guardian's home. This refers to housing bought or rented by the parent or guardian on behalf of a person, but not occupied by the parent or guardian. Families caring for members with mental retardation should have access to an array of supports,

these supports fall under the category of "family supports" as opposed to community residential supports.

Shared home. This refers to a jointly owned or rented home by two or more persons, one or more of whom is developmentally disabled. As in the case of any joint living arrangement (e.g., a married couple, college roommates), all parties are equally entitled to live in the home. Which party would move in the case of disagreements is a matter for negotiation.

Existing home and household. This includes an existing home into which one or more people with disabilities move. The traditional foster home, or "community training home," is an example of an existing home and household. Since this cannot truly be considered a person's own home, this kind of an arrangement has built-in drawbacks. As in the case of an agency facility the person remains a guest in someone else's home. Yet there are circumstances in which the advantages of moving into an existing household outweigh the disadvantages. APPENDIX III presents some common issues in traditional family care programs.

Cooperative. In a cooperative a person joins in the ownership of housing as a member of an entity.

Corporation owned or rented. For people who do not have the legal capacity to own or rent property and who do not have parents or guardians, corporate ownership or rental of housing may be necessary. Since ideally housing should be separated from support services, the corporation owning or renting the housing should be separate from one providing services.

Regardless of where people live, they should have access to a

variety of supports and services. The following are strategies for providing support, supervision, or services to people with disabilities. Note that these strategies are limited to paid support.

Agency staffing. Agency staff can provide both direct and indirect support to people. In addition to staff providing direct services, some agencies that support people in their own homes employ community resource staff who provide case coordination, assist in the management of attendants, provide training, and offer back-up services.

Live-in Staff. This includes people employed by an agency who live with people with disabilities.

On-call staff. This refers to staff employed by an agency to be on-call to provide assistance to people. On-call staff may actually live near people supported by an agency and be accessible through emergency communication systems. A live-in staff person at one home may be on-call to assist people in another.

Other staff. Other kinds of agency staffing include "drop-in" staff and staff who work specified hours.

Paid roommates or companions. Paid roommates or companions are people paid to live with and provide support to people with disabilities. A paid roommate could be a family provider ("community training home provider") who accepts a person into his or her home or someone recruited to provide support to a person in a shared living arrangement or a person's own home. In contrast to agency staff, a paid

roommate is considered self-employed. Ideally, the person with a developmental disability participates in the hiring and supervision of the paid roommate.

Paid neighbor. This can be a person from the neighborhood or apartment complex paid to provide assistance to a person with a developmental disability or to be on-call in case of emergency. Like a paid roommate, a paid neighbor could be self-employed.

Attendant. We use this term to refer to someone who is employed directly by the person with a disability. While attendant care has been commonly thought of as an option for people with physical disabilities, this approach has recently been used to support people with mental retardation and severe disabilities. Funding for attendants can be provided directly through public agencies or through private agencies contracted with to administer attendant care funds.

FIGURE III lists the major types of both housing arrangements and community supports described above. What makes this framework flexible and individualized is that theoretically any housing arrangement can be matched with one or more types of support. For example, a person with mental retardation living in his or her own apartment or a house owned by a parent can be supported by a live-in agency employee, an on-call agency employee, a drop-in agency employee, a paid roommate, a paid neighbor, an attendant or any combination thereof.

FIGURE III.

AN INDIVIDUALIZED APPROACH TO COMMUNITY SUPPORT

Separation of Housing and Support

Housing Options	Support Options
Own Home	Agency staffing Live-in On-call Other
Parent's or guardian's home	
Shared home	Paid roommates or companions
Existing home and household	
Cooperative	Paid neighbor
Corporation owned or rented	Attendant

A comparison of this approach with residential alternatives in Connecticut highlights the limitations and the potential of existing programs. First of all, private community living arrangements, in addition to combining housing and support into a single package, offer a limited choice in terms of both housing (owned or rented by the agency) and staff support (agency staff and increasingly shift staff as opposed to live-in or drop-in). Within the confines of the existing program, some providers have developed innovative strategies for supporting people; for example, a house manager living in the lower level of a duplex and accessible by phone in case of emergency; on-call staffing, with a beeper system, to support people in separate dwellings (although another provider reported that DMR regional staff disapproved the use of a beeper system for one of its clients); an apartment cluster with a live-in staff person in a separate apartment in addition to other agency

staff. Yet since private community living arrangements have been licensed facilities and required to adhere to rigid staffing ratios, both housing and support options have not been put into place.

Second, the DMR supported apartment program offers greater potential for flexibility and individualization than licensed community living arrangements. With funding from the housing subsidy program, people with mental retardation can live in a variety of housing arrangements, most notably, their own homes. While staffing can vary from drop-in to full-time support, however, support is provided exclusively by DMR staff. As illustrated by DMR's Community Living Arrangements Subsidy Program Interim Guidelines, staffing for these living arrangements follows a shift pattern.

DMR's housing subsidy program also will need to break from its tradition of being a transitional approach for people with mild disabilities. During our site visits, supervised or monitored apartments were described as being for "higher functioning people" and "borderline MRs with IQs from the mid-60s to high 80s." One regional staff member stated, "The strength of the staffed apartments is that it teaches people about apartment living and prepares them to move on." One region's supervised living program manual, while containing useful skill inventories, indicated that the program is targeted toward people with "moderate - borderline" mental retardation and described entrance criteria that would eliminate all but the most independent persons.

Finally, as discussed under the following finding, DMR's state- and privately-operated community training program has the potential

to offer a flexible and individualized approach to supporting people with mental retardation in the community. If defined broadly enough, the community training home program could be used to fund "paid roommates," including both families and individuals, for people with mental retardation living in existing households or shared homes.

It should be noted that no state has fully implemented an individualized, nonfacility-based, or person-centered approach to community living as described here. This approach has been pioneered by individual agencies, notably Options in Wisconsin and Centennial Developmental Services in Weld County, Colorado, which have bended and patched together state and county funding mechanisms. (For further information on Options and Weld County, see Johnson, Belonging to the Community, 1986; Johnson and O'Brien, Carrying Options' Story Forward, 1987; Taylor, Community Living in Three Wisconsin Counties, 1986; and Walker, Site Visit Report: Centennial Developmental Services, Inc. Weld County, Colorado, 1987). However, some states have put into place flexible funding, including creative uses of federal funds such as the Medicaid waiver, that permits the development of more individualized community supports. FIGURE IV briefly summarizes selected state initiatives that encompass some of the components described in this section.

FIGURE IV.

SELECTED ASPECTS OF INDIVIDUALIZED FUNDING AND SUPPORTS FOR ADULTS IN OTHER STATES

FIGURE IVa.

Minnesota Home and Community Based Medicaid Waiver*

Separation of Housing and Supports

1. Supports can be provided in a person's own rented or owned home as well as in an agency facility or an adult foster home.
2. A person can live in a variety of kinds of housing and still receive support.
3. A person can be involved in locating and selecting the home.
4. A person can live alone or with others and can have a choice of roommates.

Home Ownership

1. Does not encourage this to occur, but allows for providing services in a person's own home either leased or owned under certain circumstances.

Individualized Supports

1. A range of different services can be provided to adults in and out of their home, including recreation/leisure, behavior programming, community integration, menu planning and dietary, budgeting, counseling on sexuality, bus training, safety/survival skills, home maintenance and community orientation. Additionally, nursing, psychological, personal care, occupational therapy, communication consultation, behavior consultation, and related services are available.
2. Plans and budgets are developed for individual people; an average cost across people served must be maintained at the county level.
3. Amount, frequency and duration of services is dependent on the needs of individuals.
4. Services are determined through an individual planning process.

Flexible Supports

1. Contracts can be renegotiated between the private agency and the county during the course of the year.
2. Workers can be hired on temporary contracts to perform services for as long as people need those specific services.
3. Times when supports are provided can be changed dependent on the person's schedule and needs.
4. Amounts of different supports may vary over the course of the year.

FIGURE IVa. continued

Availability for People with Severe Disabilities

1. This is both a deinstitutionalization and a diversion waiver; designed for people at ICF-MR level of care; respondent indicates that some of the people with the most severe disabilities may not yet be served.

Choice in Support Providers

1. The county can contract with different providers for different services that a person may need or one provider can offer a number of different services; input of the person may be solicited before decisions on providers are made.

Issues

1. Stringent informal criteria used for determining when supports will provided in a person's own home; less than 5% of supports are offered in a person's own home.
2. Available only through the waiver.
3. No mechanisms available to allow for people to hire their own attendants or to grant money to person/family for purchases.
4. A variety of implementation issues, including maintenance of average cost at county level and change in thinking of provider community from ICF/MR model.
5. Still results in "boxes" of services; supportive living services are generally 24 hour support and are funded through the Medicaid waiver; if a person needs substantially less support, must be funded as semi-independent living through state/county funds.

*Information based on site visit 8/87, telephone interview with Medicaid waiver manager in May 1988, and waiver application.

FIGURE IVb.

Michigan Supported Independence Program*

Principles of the Program
(from Michigan Department of Mental Health Services Standards, 7/31/87)

1. The program must provide the participants with as much autonomy as possible.
2. The program must be designed to meet the needs of the participant, i.e.: location, type of residence, staff support, etc.
3. The program must be flexible and responsive to changes in the participant's needs, particularly with regard to staff support. Providers must be able to add, or withdraw support as the participant and his/her I-team deem appropriate.
4. The participant is an active member of the I-team. His/her

preferences for living situation, roommate arrangements, employment are very seriously regarded.

5. The residence (home, apartment) is that of the participant(s), not the staff or provider. Professional staff should observe the same courtesies they would entering anyone else's home.
6. Each site will serve no more than 3 people.
7. Wherever possible, the person's current I-team should continue to provide support services in their new residence.

Additional Highlights

1. The contract rate is based on the recipient's utilization of approved service categories and may be adjusted as services change.
2. Exceptions request mechanism also used for the supported independence program to increase added support when needed.
3. Program has made extensive use of home modifications to adapt places to meet the needs of individual people.
4. Assessments include a focus on: client training needs and needs for supervision/assistance, staff training needs, needs for specialized or adaptive equipment, recommended type and frequency of service contacts, recommended staffing, and needs/recommendations for special services.

Issues

1. Plans are developed for individual people, but cost centers become the home; aspects of contracting process (e.g., 95% occupancy rate) based on group as opposed to individuals.
2. Greater availability for people with severe physical disabilities as opposed to severe intellectual limitations; person must be able to live in the community without "continuous supervision" as opposed to supports.
3. Team recommendations tend to lean toward oversupervision initially.
4. A variety of implementation issues, including assisting state personnel and private providers to change to a new approach.
5. Initial lack of a mechanism for a participant to change to a new provider during the contract period if so desired.
6. No provision for the person hiring their own attendant; all staff are hired by the provider.
7. Little emphasis on building on natural supports in the community.

*Based on site visit in fall 1987 and review of statewide guidelines for the supported independence program.

FIGURE IVc.

Wisconsin Community Integration Program
Home and Community Based Medicaid Waiver*

Highlights

1. The individual assessment process is a particular strength. "The purpose of the assessment is to gather current, valid information about each specific person and his/her community environment in order to determine what service, supports, or other environmental modifications would be necessary to enable a person to live and participate in the community with as much dignity and value as possible." Areas such as informal supports, personal preferences and social participation are included.
2. There is an average amount of funds available for each person using the medicaid waiver; counties can fund some people at higher or lower amounts as long as the average is maintained.
3. Individual service plan includes different service categories, unit cost and frequency; some selected examples of service categories include personal emergency response system (CIP II), communication aids (CIP II), housing modifications (CIP IA, IB and II), adaptive equipment (CIP II), and supportive home care (CIP IA, IB, II).
4. Possible for counties to combine various funding streams to support people in the same home.
5. It is possible for a person to live in a home they own or rent and still receive supports.
6. Plans and service costs are tied to individual people; if a person moves, their funds follow them.

Issues

1. Service categories still include facility based services such as group homes, but limit of four people in a home unless a waiver granted.
2. Slow process of working with counties to change to a more individualized approach to supporting people in the community.
3. While people with severe disabilities have been served in the community through the waiver, initially there were some limitations based on the average amount of money available.
4. There does not seem to be an easy mechanism to change the supports a person is receiving in a timely way or for the person to change their provider.

*Information based on site visit in 1986 and review of most recent Medicaid waiver application.

FIGURE IVd.

North Dakota Home and Community Based Medicaid Waiver*

Highlights

1. Service costs paid for through the Medicaid waiver include habilitation (training the person in particular areas of daily living) and personal care services (assisting or maintaining the person receiving services); costs include direct care staff salaries, transportation and consulting services as well as indirect costs.
2. Individualized rates are established for each person; contract is for each person.
3. Staffing can include a variety of options including live-in staff in the person's apartment/home, direct care support hours to maintain the placement, paid neighbors, and paid companions.
4. Service intensities (for staffing) can vary from relatively minimal to 24 hour shift staff.
5. The budget is developed concurrently with the interdisciplinary team process.

Issues

1. Seems to be set up as part of a continuum of services, although eligibility criteria state that people can move directly from Grafton (the state institution).
2. Agreements are with one provider to give all supports; no mechanism appears to be set up for change during the contract period.
3. North Dakota plans to make major changes in its waiver based on its experience.
4. Case management is internal to the provider agency.
5. All direct care staff must be employees of the contracting providership; no option for the person with a disability to employ; all relationships defined as employer-employee relationships.

*Information based on review of written material; site visit to take place fall 1988.

FINDING 12. The community training home funding mechanism has the potential to increase the individualization and flexibility of residential services operated by private providers.

As part of an administrative and fiscal restructuring of the community training home (family care) program, which historically has been a state operated program, DMR has authorized the

reimbursement of private providers to manage community training homes. DMR's five year plan has a goal to fund at least ten private providers to manage "clusters" of community training homes by 1989.

Under the revised rate structure for community training homes, DMR has increased significantly the amount and flexibility of funds for community training homes. According to the new structure, community training homes are reimbursed according to three separate rates, including both a basic DIM rate and a DMR supplement: less than 24 hour supervision ($24.55 per diem); 24 hour supervision ($31.15 per diem); and ongoing comprehensive support ($39.27 per diem). The funding structure also provides for individualized adjustments to pay a special support rate for additional services and for an allotment for respite or relief for each community training home.

The private operation of the community training home program has the potential to expand the housing and support options used by private providers to support people in the community and, hence, to enhance the flexibility and individualization of private sector residential services. As noted above, the private community living arrangement program has been limited to agency operated facilities staffed by agency employees. Through the community training home program, private providers can expand housing options to include "existing homes or households," and possibly "shared homes," and support options to include "paid roommates," including families (see FIGURE III above).

In the phone interviews, we identified two private providers who were operating community training homes. Of the remaining 11

providers, six indicated that they had no plans to become involved in the program, while five stated that they were open to the program, depending upon the funding and administrative requirements of DMR. Of the two providers operating community training homes, one reported that the agency had been unsuccessful in finding families for people with severe disabilities and currently was placing more independent people. The other provider operated a "professional parent" program and had placed one young boy with difficult behavior and planned to place nine additional children, some of whom have severe disabilities. Since the provider had received many more referrals than anticipated, he expected that the program would grow beyond the ten children originally planned.

As the name suggests, the "professional parent" program operated by this provider was designed to recruit highly skilled and trained foster parents for children with mental retardation and especially those with severe disabilities. According to the provider, an assessment device is used to determine the stipend provided to parents, with a minimum set at $20,000 per year. The assessment device assigns points based on the the needs of the child (for example, functional level, medical or behavioral problems) and skills and experience of the parents (for example, college degrees). Based on the children and parents identified to date, the stipend averages $27,000 to $32,000 per year, although the provider anticipates that the rate may exceed $40,000 per year in the future. The provider is also funded for administrative costs, program supplies, staff travel, and other costs. Homes are licensed by DMR.

As reported by the operator of the "professional parent" program, one of the major problems of the program was dealing with natural, or birth, parents: "Parents sometimes have second thoughts and feel guilt. The agency gets caught in the middle." Since a private provider operating a community training home program may not be in the best position to work with parents in deciding the future of their children, it is critical that DMR regional staff help negotiate between the natural parents, foster parents, and providers operating community training home programs. As recommended in our evaluation of DMR's community training home program, DMR should develop policies and guidelines on "permanency planning."

While a "professional parent" model represents only one of the possible ways in which a private community training home program might operate, this program illustrates how the community training home program can be used to introduce flexibility into private sector residential services. The private community training home program enables the provider to break out of a facility-based approach. Whether or not professionalization of the parental role is appropriate, this provider is attempting to design the program around the needs of individuals. The provider is funded through an individually negotiated rate that includes both stipends to parents and agency costs. In our review of the funding of private providers, this is the closest we have seen to a truly individualized rate-setting structure. The cost center is not a facility, but rather the individual.

In view of the fact that the private community training home program is a new initiative, regional staff and private providers

may not be aware of ways in which the program can be used to fund innovative alternatives to private community living arrangements (as opposed to being a "foster care program"). In addition, as a new initiative, the program has not been conceptualized fully. It is unclear what the limits of the program are today. For example, can the program be used to fund "paid roommates" in homes jointly owned or rented or to pay for an attendant or a "paid neighbor" to support a person in his or her own home? To realize the full potential of the program, DMR will need to provide clear guidelines on the administration and funding of the program and how it can be used to develop individualized community supports.

FINDING 13. The definition of community living arrangements in terms of three categories, "Assisted," "Supervised, and "Ongoing Comprehensive Support," is likely to be interpreted in a manner that undermines DMR's intent.

DMR has undertaken a major restructuring of rate-setting and licensure regulations for private community living arrangements. As part of this restructuring, DMR has defined community living arrangements in terms of three level of service categories, "Assisted," "Supervised," and "Ongoing Comprehensive." Earlier in this report, we discussed the fact that at the time of the review DMR Central Office and regional office officials did not share a common understanding of the meaning of these three levels of service. Some regional officials viewed the three levels as unrelated to rate-setting; some regional officials viewed them as "caps"; and some regional officials viewed them as "guidelines" or "artificial caps." Private providers either have not heard about

these three categories or are unclear about what they will mean for their funding.

When operationalized in the context of a "facility-based" residential system, the definition of community living arrangements in terms of these three categories is likely to perpetuate a "continuum" approach and undermine DMR's intent to move towards a more individualized community service systems. By a "continuum" approach, we mean not only a "transitional" or "readiness" model, but also a model that defines services as "program boxes" into which people must fit. During site visits and phone interviews, a number of regional staff and private providers described private and state operated community living arrangements in terms of preparing people to move to more independent and less restrictive environments. Even stronger, however, was a tendency to confuse service needs with facility types; in other words, the assumption that a person's disabilities should determine the kind of facility in which the person will live. The danger is that the levels of "Assisted," "Supervised," and "Ongoing Comprehensive Support" will be operationalized not in terms of services, but in terms of types of facilities. As described in the Community Living Arrangement Guidelines for DMR programs, "Assisted," "Supervised," and "Ongoing Comprehensive" refer to types of CLAs, each with a model staffing pattern. (Note that the use of these levels of service in the community training home program has less of a tendency to become rigid, since community training homes are homes and not facilities.)

As we understand it, the intent of the three levels of Assisted, Supervised, and Ongoing Comprehensive is to relate needs to

support. The basic distinction is between Assisted and Supervised. Assisted applies to people who do not require overnight supervision; Supervised applies to those who require 24-hour supervision; Ongoing Comprehensive applies to those who require 24-hour supervision and something more. Yet the distinction between who does and does not need round-the-clock support is not as simple and straight-forward as it might seem.

In the first place, as discussed earlier, the current community residential system is geared toward over-protection. Many regional staff and private providers, although certainly not all, have attempted to create "risk-free" environments for people with mental retardation, places in which people are protected from the ordinary risks of living. The reasons cited for overnight, and often awake night, supervision of people range from serious behavior problems to poor judgment to a lack of independent living skills: might bring home bad friends, might drink, might smoke in bed, cannot cook, cannot use the phone, does not have community mobility skills.

In the second place, acknowledging that many people with mental retardation will require support or supervision, the distinction between Assisted, Supervised, and Ongoing Comprehensive support detracts attention from the strategies that can be used to support people. In other words, the distinction directs attention to the question, "Do people require 24-hour supervision or don't they?" As such, the question will be answered in terms of a checklist of skills or characteristics. Since many people will not have the requisite independent living skills, 24-hour supervision will be provided. A more important question is: "What strategies can be

used to provide support as unobtrusively as possible?" For people who might fall under the category of "Supervised," the range of support strategies includes live-in staff, awake night staff, on-call staff, intercom systems, life-call systems to emergency services, speed dialing telephones, paid neighbors, paid roommates, and others. Whether a person will require 24-hour staff supervision will depend not only on the skills and characteristics of the person, but on what alternative strategies are available.

RECOMMENDATIONS

In this section of the report, we present our recommendations for private community living arrangements in Connecticut based on our study findings. Since many of our recommendations cut across the three study questions--the costs of the most expensive private community living arrangements, the level of supervision provided in private community living arrangements, and the flexibility and individualization of the private community living arrangement program, we do not present these recommendations according to the organization of the findings.

RECOMMENDATION 1. DMR should continue to direct resources to community living arrangements to correct its historical bias in favor of institutions.

Like other states, Connecticut's public spending for mental retardation and developmental disabilities services has been marked by a distinct institutional bias. The vast majority of resources have been directed toward the state training schools and regional centers, rather than to home and community-based services. The average costs of the institutions have been significantly higher than the average costs of community programs.

As a matter of policy, we recommend that Connecticut make the same level of resources available to support individuals in community programs as it does in institutions. In many cases, the average costs of community programs will be lower than institutions, while in some cases they will exceed the average costs of

institutions. Available data indicates that the average costs of even the most expensive private community living arrangements are in line with the average costs of institutions.

It should be recognized that the average costs of community living arrangements are to be expected to vary widely. Community living arrangements for some people will cost significantly more than for others. A narrow focus on the costs of the most expensive programs will present a misleading picture of the funding of community living arrangements.

RECOMMENDATION 2. DMR should continue to strengthen the role of the regional offices in negotiating budgets with private providers.

Under the Level of Care system, rate-setting for private providers was highly centralized. State regulations set rate "caps" for each of five levels. In order to exceed the cap, a waiver was required by the Commissioner of the Department of Income Maintenance upon the written request and justification of the Commissioner of Mental Retardation. As concluded in this study, the Level of Care system was inflexible and rigid.

DMR's new rate-setting system calls for the regions to assume increased responsibility for negotiating rates with private providers operating community living arrangements. Within available resources based on regional allocations, the regions will be responsible for negotiating individual rates with service providers. DMR will be able to control costs through the regional allocation rather than an arbitrary rate cap.

Based on our meetings and interviews with regional office officials and staff, we believe that the regions are capable of

negotiating reasonable rates with private providers given the current design of community living arrangements. Since the new rate-setting system is new and licensure regulations are under revision and in view of the findings of this study, we believe that DMR should continue to provide further clarification and guidance to the regions to assist them in rate negotiation.

RECOMMENDATION 2A. DMR should clarify that the categories of Assisted, Supervised, and Ongoing Comprehensive Support are not caps or guidelines.

Considerable confusion surrounds the relationship between the three categories of service and the rate-setting system, with at some regional officials believing that the categories represent "guidelines" or "artificial caps." In view of the fact that Central Office envisions a limited relationship between the categories and rates, this should be stated explicitly.

RECOMMENDATION 2B. DMR should clarify that private providers will be able to shift resources among cost categories.

While the ACOR indicates that the community living arrangement is the cost center, recent information provided by DMR indicates that private providers will have the flexibility to shift resources among cost centers or, in other words, from one community living arrangement to another after the rate has been negotiated. DMR should clarify this in writing to regional offices and providers.

RECOMMENDATION 2C. DMR should strengthen the capacity of regional staff to negotiate with private providers regarding staffing costs.

Since direct staffing represents the major cost of private

community living arrangements (and accounts for 75.1% of the cost differential between "overcap" and "non-overcap" programs), budget negotiations with private providers should focus on staffing costs. Our review of private facilities points to two areas that warrant special scrutiny: first, the cost of shift and especially awake night staff; and second, the cost of professionals providing direct care.

The revisions in the licensure regulations eliminating the rigid staffing ratios under the Level of Care system will provide an opportunity to review the staffing of private community living arrangements. Private providers should be encouraged to substitute live-in staff for shift staff and asleep staff for awake night staff unless specific justifications are provided. Similarly, private providers should justify the use of professionals as opposed to trained for a professionals to provide direct services. A decision-making framework for determining supervision is presented under RECOMMENDATION 6. The "residential client needs assessment" referenced in the draft rate-setting regulations for private community living arrangements might be used to address these issues.

While a minor cost compared to staffing, DMR might also encourage the regional offices to undertake a review of the transportation costs of private community living arrangements. As a routine matter, each private community living arrangement apparently purchases or leases its own vehicle. This may be necessary for many programs, but alternatives such as the shared use of vehicles or the use of public transportation should be explored before the acquisition of a vehicle for an individual facility.

RECOMMENDATION 3. DMR should continue to encourage the development of smaller settings.

One-, two-, and three-person settings offer a greater potential for individualization than larger settings. The costs of smaller facilities appear to be higher than larger ones; however, factors other than size may account for the cost differential. No definitive conclusion concerning the relationship of cost and size of setting can be reached without an examination of factors such as severity of disability of people served and staffing patterns.

While we recommend that DMR continue to encourage and fund the development of smaller facilities, we are also recommending that DMR support the development of "nonfacility-based" services, which, in many cases, will be less expensive than shift-staffed facilities.

RECOMMENDATION 4. DMR should abandon the definition of community living arrangements in terms of the categories of Assisted, Supervised, and Ongoing Comprehensive Support.

At the same time that DMR is attempting to move away from an inflexible level of care system, the definition of community living arrangements in terms of Assisted, Supervised, and Ongoing Comprehensive Support threatens to undermine DMR's intent. It is likely that these categories will be interpreted as a continuum of community living arrangements. Since the new rate-setting system and draft licensure regulations do not use these categories, and appropriately so, the utility of this distinction is unclear.

RECOMMENDATION 5. DMR should work with the Connecticut Department of Labor to revise Connecticut labor laws that may contribute to unnecessary program costs and reduce flexibility.

The Connecticut labor laws are more restrictive than federal wage and hour standards, particularly regarding issues such as live-in staff. It is critical that the Department of Mental Retardation work with the Connecticut Department of Labor to examine this issue.

RECOMMENDATION 6. DMR should provide guidelines to assist regional offices, interdisciplinary teams, and private providers in making decisions regarding the level of supervision provided in private community living arrangements.

As a general rule, private community living arrangements are geared toward over-supervision. First, in accord with the Level of Care system and existing licensure regulations, awake night supervision is provided in many community living arrangements in the absence of justification. Second, there is a sizeable, though unknown, number of people who, according to private providers, do not require the level of supervision provided in their community living arrangements. Third, additional people who appear to be relatively independent (for example, travel alone in the community) are living in facilities that provide 24-hour supervision. At least some community living arrangements appear to be over-protective regarding overnight supervision. Fourth, under the existing private community living arrangement program, providers have been limited in their ability to employ alternative strategies, such as on-call staff, for people who require a level of support between independent living and on-site staff.

With a new rate-setting structure and licensure regulations, regional offices and private providers will require guidelines for making decisions regarding supervision. As noted under the

findings, DMR cannot assume that changes in rate-setting and licensure regulations eliminating levels of care and staffing ratios will automatically result in changes in the level of supervision actually provided in private community living arrangements. Under the Level of Care system, the RET process assigned a level to a person which in turn determined the supervision. An alternative process will be required under the new rate-setting system and licensure regulations.

The "Residential Client Needs Assessment" provides a potential process for decision-making regarding supervision and support needs. (Since we have not received a copy of this assessment, we are unaware if it has been developed). The following are our recommendations on how this assessment might be used to make determinations.

First, the interdisciplinary team ("IDT") should complete this assessment as part of the individual plan (OPS) for each person. In contrast to the past when staff ratios and supervision were determined separately from the OPS process, we believe that decisions regarding supervision should be made in the context of the overall plan for an individual. Decisions should be made by professionals, family members, and advocates who know the person, in addition to the person him- or herself. While forms and rating instruments may aid decision-making, there is no substitute for the reasoned judgments of people who have personal knowledge of the person.

Second, as implied above, the "Residential Client Needs Assessment" should start with an assessment of each individual. As

described in draft regulations, the "Residential Client Needs Assessment" presents a "composite assessment" based on the community living arrangement. This may present a misleading picture of the range of needs of people within a community living arrangement. The staffing of a community living arrangement, as a group facility, will necessarily be based on composite needs. However, prior to assigning staff to a community living arrangement, the individual needs of people living within a facility should be identified.

Third, the assessment should differentiate between supervision needs and other needs for staff support. A basic flaw of the RET process was that it used criteria unrelated to supervision needs to determine level of supervision. A person was rated on such characteristics as eating skills, dressing skills, food preparation, laundry/housekeeping, and money management. While a lack of skills in these areas may point to needs for staff support during the course of the day, this is not necessarily related to needs for supervision especially during the night. For example, a person may not be able to cook, but be perfectly capable of living safely in his or her own home. One region's manual for state supervised apartments also describes entrance criteria (e.g., travel independently in the community; cooking) unrelated to supervision.

The assessment should be directed to two questions: (1) Is the person capable of living safely in a home, with accommodations? and (2) Does the person require support and assistance in daily living skills? Since at least some regions have developed extensive skill inventories to answer the second question, we focus our attention on the first question.

FIGURE V.

SAMPLE DECISION-MAKING FRAMEWORK FOR DETERMINING SUPERVISION AND SUPPORT

ONE	
The person requires medical care/intervention during the night.	YES-Provide awake night support. Collect data and review on regular basis.
or	
The person evidences behavior at night which if not immediately attended to would result in injury or harm to the person or others	NO-Proceed to Step Two.
TWO	
The person is unable to recognize emergency situation or hazards.	YES-Provide on-site nighttime support (staff or paid roommate). Collect data and review on a regular basis.
or	
The person evidences behavior at night which if not attended to within reasonable period of time would result in injury or harm to the person or others.	NO-Proceed to Step Three.
THREE	
The person is unable to evacuate residence on his or her own.	YES-Determine support strategy: (1) on-site nighttime support (staff or paid roommates); (2) on-call staff (nearby) (3) paid neighbor; (4) emergency communicatio system. Review on a regular basis.
	NO-No nighttime support required. On-call support available.

FIGURE V contains a sample decision-making framework for determining the level of supervision required by a person. The framework is oriented towards nighttime support, but could be used to make decisions regarding support required during the day. Note that this framework is not intended to be exhaustive (there may be other considerations), but simply illustrative.

This framework contains a three step review process. Step one is to decide whether the person has a medical condition that requires nighttime intervention or has a behavior occurring at night that if not attended to immediately would result in injury to the person or another; if yes, provide awake night supervision; if no, proceed to Step two. Step two is to decide whether the person is unable to recognize emergency situations or hazards or has a behavior occurring at night that if not attended to within a reasonable period of time would result in injury to the person or another; if yes, arrange for on-site nighttime support; if no, proceed to Step three. Step three is to decide if the person is unable to evacuate a residence on his or her own; if yes, determine support strategy, including on-site nighttime support or on-call, nearby staff or paid neighbor with emergency communication device; if no, no nighttime support is required, on-call support available.

Fourth, for a community facility, a composite needs assessment can be developed based on individual assessments, to determine the level of supervision required in a community living arrangement. A composite will necessarily determine supervision based on the person in a community living arrangement with the most intensive needs. For example, at a community living arrangement in which half the

people require awake night support and the other half do not, it would be meaningless to compute an average need ("half-asleep staff").

Fifth, through a comparison of individual assessments and the composite assessments for a community living arrangement, people living at community living arrangements providing more supervision than they require can be identified. Recognizing that people may choose to continue to live at settings that provide more supervision than they require, a determination should be made whether alternative living arrangements should be pursued.

RECOMMENDATION 7. DMR should undertake a thorough review of statutes and current and draft rate-setting and licensure regulations for private community living arrangements and the community training home program to determine if they permit private providers to offer individualized services for people with mental retardation.

By its design, the private community living arrangement program has been an inflexible program. A private community living arrangement has been an agency operated and staffed, licensed facility.

With the changes in rate-setting and licensure regulations and with the funding of private community training home programs, DMR has the opportunity to enhance the flexibility and individualization residential services operated by the private sector. Under the findings of this study, we contrasted "facility-based" and "nonfacility-based" or "individualized" approaches to supporting people with mental retardation in the community. Based on our

understanding of funding and rate-setting regulations, we are not clear whether the changes DMR is contemplating will provide sufficient flexibility to enable private providers to offer individualized services. If interpreted narrowly, the regulations would appear to preclude many options. However, if interpreted broadly, they might permit private agencies to pursue a range of innovative strategies for supporting people with mental retardation. DMR is in the best position to interpret its regulations and to work closely with the Office of Policy and Management and the legislature, if changes are necessary in the statutes.

An individualized approach requires a separation of housing and support, with a range of both housing and support options. The following are some of the fiscal, statutory and licensure issues that require clarification in regard to housing and support options.

Housing Options

Own home. Private community living arrangements have been equated with licensed facilities owned or rented by the provider. The draft rate-setting regulations define community living arrangements and community training homes as licensed residences. According to DMR, this is based on current statutory language that prohibits funding of private providers for residential services offered outside of licensed community living arrangements or community training homes. In contrast, DMR currently supports people in their own homes through the state supervised apartment program. This flexibility must also be available to the private providers. While the housing

subsidy has been used in conjunction with state supervised apartments, nothing in the housing subsidy regulations would appear to prevent people supported by other providers from receiving the housing subsidy.

Parent's or guardian's home. Note that this applies to a home rented or owned by the parent or guardian, but in which the parent or guardian does not reside. Can providers provide residential services in unlicensed homes owned or rented by a parent or guardian and funded through individual or family resources?

Shared home. Can a home jointly owned or rented by a person with mental retardation and another person be licensed as a community training home or a community living arrangement (in New York, supportive apartments rented by a person with developmental disabilities can be licensed)?

Existing home and household. Clearly, an existing home can be licensed as a community training home.

Cooperative. Can a private provider be funded to offer residential services to a person living in an unlicensed cooperative if jointly owned by a person with mental retardation or their guardian?

Corporation owned or rented. A private community living arrangement has often been a corporation owned or rented facility with staff employed by the same corporation. Nothing appears to prevent a private provider from offering residential services to a person living in a home owned or leased by another agency (e.g., parent association).

Agency staff: Live-in; On-call; Other. DMR's draft rate-setting and licensure regulations would appear to permit a broad range of agency staffing options for at least licensed facilities. Can agency staff support people in unlicensed settings?

Paid roommates or companions. Paid roommates or companions could be funded under the community training home program.

Paid neighbor. Can a paid neighbor living in a nearby house or apartment be funded under the community training home program or through a private provider's budget?

Attendant. Under the community training home and community living arrangement programs, can funding be provided to pay for attendants employed by a person with disabilities?

As this discussion suggests, the major questions regarding the flexibility of the private community living arrangements and community training home programs are: (1) Can private providers be funded to provide residential services to people living in unlicensed homes? and (2) Can funding allocated to providers be used to pay for paid neighbors or attendants employed by people with developmental disabilities?

RECOMMENDATION 7A. Based on this review, DMR should pursue authorization by statute and/or regulations to provide an array of support services in a variety of housing options (e.g., in a person's owned or leased home).

If DMR interprets the state statutes and regulations to permit a range of housing and support options, then it should communicate this interpretation to regional offices and private providers. If,

on the other hand, DMR concludes that the statutes and regulations will preclude unlicensed housing or an array of support options, it should work cooperatively with the Office of Policy Management and the legislature to revise the statutes and/or regulations.

We are recommending that DMR incorporate an individualized approach within the framework of existing private sector programs. An alternative is to develop a new funding mechanism to support nonfacility-based, individualized supports. While it is generally easier to develop a new program than to reform and revise an old one, our experience is that "supervised" or "supportive" living programs tend to be interpreted as another step in the continuum of residential services and implemented in a way that excludes people with severe disabilities. Rather than to propose the creation of a new "program," we recommend increasing the flexibility of the existing framework to include individualized as well as facility-based services.

RECOMMENDATION 8. DMR should develop guidelines for individualized supports for people with mental retardation.

Especially since private providers have operated within the confines of a rigidly defined community living arrangement program in the past, DMR should develop guidelines to assist providers to offer individualized services. As DMR has done to address other issues, one way to develop guidelines is to convene a statewide work group. We recommend that the work group be composed of DMR Central Office officials, regional office officials, private providers, and parent and consumer representatives. In view of its experience in housing, the Corporation for Independent Living might also be

invited to participate in this work group.

The following are some of the major issues that might be addressed in the guidelines.

The relationship of individual planning to funding. Under the current and proposed rate-setting systems, funding is not directly connected to individual planning. An individualized approach will require a close relationship. The "cost center" should be the individual, not a facility or agency. Steps in individualized rate-setting might include: (1) individual needs assessment; (2) individual plan (OPS); (3) determination of housing costs (also see the discussion below), direct support costs, additional staffing costs (e.g., coordination, relief, assistance in attendant management, recruitment of paid roommates or attendants), agency costs; (4) review of costs in light of available resources; (5) individual rate. (While we are proposing a process along these lines for individualized services, we are not necessarily recommending the same process for facility-based community living arrangements.) As is currently the case, regions will be required to negotiate costs of services within the resource limitations of regional allocations.

The payment of housing costs and other household expenses. As noted under the findings, the housing subsidy program is an innovative state mechanism to assist people to live in their own homes. The housing subsidy should be available to people supported by private providers. As indicated in DMR's guidelines for state community living arrangements, the consideration of the housing subsidy as income by DIM should be resolved on a policy level. In

addition to assistance in meeting housing costs, some people will require financial assistance to pay for furniture, phone systems and communications devices, furnishings, and household expenses. People should have the opportunity to own their furniture and household goods. A grant or loan program might be established to assist people in meeting these expenses.

The expansion of housing options. Listed under the housing options we have identified are cooperatives and housing owned or rented by a corporation on behalf of an individual. The use of these options may require creative financing approaches and legal assistance. While the Corporation for Independent Living (CIL) has focused on the construction and renovation of facilities for people with mental retardation, it might be called upon to play a new role in assisting DMR and private agencies in exploring new housing options. In addition, recognizing that accessibility standards for individual homes must vary from those for facilities, CIL might provide consultation on making cost-effective renovations to existing housing and financing adaptations.

The provision of flexible supports. Since private providers have relied exclusively on agency staff and increasingly shift staff, they will require guidance on providing flexible and individualized supports to people through live-in and on-call staff, paid roommates, neighborhood support workers, and attendants. The Options manual, Belonging to the Community (Johnson, 1986), is an excellent resource on flexible supports for people with disabilities.

Licensing and quality assurance. Supporting people in a range

of housing options, including their own homes, raises serious questions for licensing and quality assurance. While agency operated facilities and existing homes (community training homes) should be licensed, it is restrictive and intrusive to require people to live in licensed facilities as a condition of receiving services. Yet at the same time, it is reasonable to expect minimal safeguards to be in place. DMR might consider licensing agencies or support personnel as opposed to settings for providers that support people in their own homes and require agencies to conduct reviews of the quality of life of the people they support. Options has developed a thorough quality of life review for the people it supports in the community (see Johnson, 1986).

RECOMMENDATION 9. DMR should explore incentives for private providers to develop individualized community supports.

As with any new approach, the development of individualized supports may require major efforts on the part of existing providers. In order to encourage providers to develop new supports or convert existing services, DMR might fund modest ($5,000 to 10,000) planning and development grants for providers. These grants might be used to fund visits to agencies in other parts of the country, to train staff, or to obtain consultation.

In the findings of this report, we described what is referred to as the problem of "backfilling," replacing a person in a community living arrangement with a person with more severe disabilities. In view of the number of people in private community living arrangements receiving more supervision than they require, DMR might encourage providers to continue to provide services to people who

move from community living arrangements to other housing options by offering to maintain the current rate for those people and increasing the rate to accept others.

RECOMMENDATION 10. DMR should consider disseminating regular policy memoranda to regional offices and private providers, particularly regarding new initiatives.

Throughout this report, we indicated that there is often a gap in what DMR intends and how regional offices and private providers interpret those intentions. As one moves from Central Office to the regional offices to providers, interpretations of policies and regulations can vary dramatically. One example is the relationship of the three categories, Assisted, Supervised, and Ongoing Comprehensive, and rate-setting.

DMR might consider preparing brief policy memoranda or fact sheets explaining new initiatives or confirming previous interpretations. These policy memoranda would be less formal than regulations, but more formal than newsletter articles. Especially as DMR proceeds with new initiatives, it will be critical for regional offices and private providers to share the same understandings of Central Office. While the Commissioner's public forums with providers have helped open communication channels with "the field," it is also important for explanations and interpretations of DMR policies to be communicated simply and straight-forwardly in writing to regional offices and providers alike.

CONCLUSION

As indicated in the Introduction of this report, this study was directed toward three broad questions concerning private community living arrangements funded by the Connecticut Department of Mental Retardation. Each question is complex and defies a simple or simplistic approach. In concluding this report, however, let us briefly summarize the answers that it has taken this entire report to present.

First, are the costs of the most expensive private community living arrangements justifiable? Given the constraints of the rate-setting system and licensure regulations that have been in place up until now and given the comparative costs of institutionalization in Connecticut, our judgment is that the costs of these programs <u>are</u> justifiable.

Second, do people living in private community living arrangements receive more or less supervision than they require? Based on our review, we have concluded that the current system of private community living arrangements is oriented toward providing more supervision than people require and that many people are in fact "over-supervised."

Third, does the design of privately operated community living arrangements provide for sufficient flexibility to meet the needs of people with mental retardation? Our conclusion is that the private community living arrangement program has lacked flexibility and individualization. In view of changes in the system of private

residential services proposed by DMR, we believe that an important opportunity exists today for DMR, together with private providers, to move toward a more flexible, individualized, and responsive approach to supporting people with mental retardation in the community.

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APPENDIX I

Methodology

The evaluation was specifically designed to address the study questions developed by the Connecticut Department of Mental Retardation. The design has both "qualitative" and "quantitative" components and is primarily "formative" in nature.

By "formative," we mean that we were interested in examining how the system currently works and to explore ways in which it could be strengthened. In particular, we focused on the issues of costs, supervision and flexibility of the privately operated community living arrangements.

By "qualitative," we mean we attempted to learn about the operation of the private community living arrangements from the various perspectives of DMR staff, private service providers, and others. All interviews were conducted based on open ended guides, rather than structured instruments or rating scales.

By "quantitative," we mean that we examined and analyzed fiscal and statistical information provided by the Connecticut Department of Mental Retardation, private providers, and information from other states.

The evaluation included a review of documents, visits to private and state operated community living arrangements, on-site interviews, fiscal analyses and phone interviews, as described below:

1. Review of Connecticut documents. As part of the evaluation, we reviewed a wide range of documents, including current and proposed DIM and DMR regulation, DMR fiscal and statistical information on

community living arrangements, DMR five year plan, DMR residential services manual, DMR Community Living Arrangements: Interim Guidelines, DMR subsidy information such as the draft regulations, memoranda between DMR central office and the regions, ACOR operational manual, information on the community training home program, relevant correspondence from the Mansfield case monitors, written information provided by several regional staff and private providers such as guidelines for assisted programs, staffing patterns, and program information, information of the Corporation for Independent Living, and information on the community training home program.

2. Phone interviews with DMR regional directors. Each regional director was contacted regarding a phone interview. Interviews were conducted with four of the six regional directors by phone.

3. Phone interviews with private service providers. Seventeen private service providers, representing all DMR regions and organizational sizes, were randomly selected for interviews. Thirteen interviews were completed by phone and two on-site. Two people could not be reached.

4. Phone interviews with other knowledgeable people in Connecticut. We conducted phone interviews with 5 additional people identified as being knowledgeable about different aspects of the study. These included a staff member of the Department of Income Maintenance, three DMR staff, and a representative of the Corporation for Independent Living.

5. Meeting with DMR assistant residential directors. We conducted a half day session with this ongoing group to assist in identifying

the critical issues in the study based on their experiences in the regions. Several members of the central office staff and other regional staff were also in attendance.

6. On-site visits to state and private-operated community living arrangements. The evaluation included visits to community living arrangements selected by DMR regional staff in four of the DMR regions. Specifically, nine privately operated (eight - 24 hour supervised homes; one - 24 hour supervised apartment site), three subsidized (less than 24 hour supervision, state monitored) apartments, and one community training home were visited.

7. On-site interviews with DMR staff and private service providers. During the visits, an additional sixteen interviews were conducted with DMR staff (including case managers, liaisons with private sector, staff responsible for the community training homes, regional management staff, and staff responsible for the state community living arrangements), and eleven with private service providers (including management staff and house managers).

8. Review of additional documents. We reviewed a number of applicable documents from other states including selected home and community-based medicaid waivers and residential program information. We also reviewed information regarding economic measures as they pertain to Connecticut.

9. Phone interviews with knowledgeable people in other states. Additional information applicable to this study was gathered through phone interviews with selected officials in other states, primarily to clarify written information and/or to obtain information on specific issues, such as supervision.

10. Fiscal comparisons and analyses. The study also included the analysis of 29 overcap agency budgets of the 37 randomly selected budgets provided by DMR; a comparison of overcap and undercap budgets for private community living arrangements; and a comparison of overcap budgets to other facility budgets for people with mental retardation.

In addition, the evaluation also draws on extensive information gained through our ongoing study of community living arrangements nationally. These studies are conducted by the Center on Human Policy's Research and Training Center on Community Integration, sponsored by the National Institute on Disability and Rehabilitation Research.

We would particularly like to thank Barbara Pankosky of the Connecticut Department of Mental Retardation for coordinating our visits to the regions and for collecting relevant background information. Thanks also to the many DMR staff, private providers, and others who shared their perspectives with us, and to Betsy Root, Cynthia Colavita, and Rachael Zubal for their work in preparing this document.

APPENDIX II

Common issues in family care

by Steven Taylor and Julie Ann Racino, Center on Human Policy Syracuse University August 1987

During the past two years, the Center on Human Policy, through its Community Integration Project and Research and Training Center on Community integration, has identified innovative community programs nationally and provided technical assistance on the development of community services to states and communities. This article is based on the experience of the Center on Human Policy with foster or family care for people with developmental disabilities and examines selected issues in foster care.

Selected issues in foster care

Many of the issues in family or foster care for people with developmental disabilities are applicable not only to a single program, service system or state, but are common to all or most family placement programs.

Lack of a mission statement for foster care

The mission of foster care is unclear in most states. As a result, regional, state, county and private agency staff involved in foster care often do not have sufficient guidance on the purposes and potential role of foster care in the system of services for people with developmental disabilities. When should family placement as opposed to other living arrangements be pursued? When is family placement appropriate for adults? What should the relationship be between foster families and natural families for children? What are reasonable expectations for foster families? When the mission of foster care is unclear, states and agencies are likely to turn to foster care because it is expedient and relatively inexpensive as compared to other kinds of community living arrangements. However, this is often done at the sacrifice of quality and exposes people with developmental disabilities to inappropriate placements.

Foster care programs typically confuse the needs of children and adults.

In most states, there is little distinction between family care for children and adults. While the foster care "model" is an appropriate one for children, only under certain circumstances (e.g., due to an existing relationship, a strong personal need to live with a family or a lack of any community ties) should an adult typically move into the home of an existing family. The most innovative places, nationally, recognize that adults often will live with roommates or alone and should have the option of having their own or a shared home.

Lack of permanency planning for children

In 1980, Congress passed the *Adoption Assistance and Child Welfare Act (PL 96-272)* that requires state social service agencies to periodically review the status of children in foster care with a view towards obtaining a permanent home for each child through family reunifications, adoption or permanent foster care. Since most mental retardation and developmental disability agencies do not receive funds under *P.L. 96-272*, in many states no provisions exist for permanency planning for children in foster homes operated under their auspices or through their grants or contracts. As a result, opportunities for reunification with natural families and adoption may not be pursued for children. By contrast, some states, notably Michigan, have developed permanency planning programs for all children with mental retardation in out-of-home care, including specialized foster care.

The relationship between social services and developmental disabilities foster care

Regarding children with developmental disabilities, one major policy issue confronting state mental retardation/developmental disabilities departments relates to whether foster care will be offered under their auspices or that of the department of social services. The arguments in favor of foster care operated by social services departments include: (1) this is a generic approach to services and; (2) social services departments are more experienced with permanency planning and adoption than most mental retardation/developmental disability agencies.

The arguments against the use of social service departments for foster care for children with developmental disabilities include: (1) social services departments may be limited to serving children who are abused, neglected or abandoned; (2) social services departments may lack the commitment to recruit homes for children with developmental disabilities and; (3) social services departments may resist assuming responsibility for children with developmental disabilities, especially those currently living in homes or facilities funded by mental retardation/developmental disabilities departments.

While ideally children with developmental disabilities who require foster home placement would be served by social service departments, this may not be feasible. In other words, if the state mental retardation/developmental disabilities agency does not play an active role in foster care for children with developmental disabilities, these children may not have the opportunity to live with foster families.

Lack of adequate supports necessary to insure successful placements

Foster families in many states are often "out there on their own" without receiving even minimal supports. Many families had no or limited access to respite. Flexible supports tailored to the needs of the individual families were typically not available. Even in situations where a specialized foster care situation was arranged, little support might be provided.

In addition, training in the area of foster care is often not available, or when available, not usually tailored to the specific needs of the families. The training itself may not differentiate between the needs of children and adults living in foster homes, may not include pertinent areas such as community participation and may be modeled after institutional training. An individualized training approach is seldom incorporated as a significant part of the training.

Funding mechanisms

Many states have used foster care or family placement because this is an inexpensive form of service. A strong case can be made that foster or family placement is significantly less expensive than institutions, group homes, supervised apartment programs and other residential services. However, many states have made the mistake of allocating insufficient resources to the operation of family placement programs. Yet, "cheap is expensive." That is to say, to underfund family placement programs is to increase overall system costs. For example, if sufficient resources are not available for family placement programs, people with severe disabilities will be excluded from this option and will be served in other settings at significantly greater cost.

Payments to foster families may vary dramatically from region to region, from county to county, within regions or counties, and from private agency to private agency, often within the same state. Most states, in practice, do not seem to have a fair and equitable rate structure for setting payments to foster families. In addition, regions, counties and private agencies may vary dramatically in terms of the support services available to foster homes.

Lack of a coordinated system of foster care

Without a unified, coherent and coordinated system of foster care, many states are likely to experience a series of major problems: (1) the potential of existing family homes for people with developmental disabilities will be underutilized; (2) people with developmental disabilities who need or want to live in an existing home will be denied the opportunity to do so; (3) the quality of homes will be substandard; (4) inequities may persist in the resources allocated across and within regions and agencies; (5) the foster care program will be driven by expedience rather than appropriateness.

Recommendations

In order to address the issues raised earlier in this article, the following recommendations are made.

Mission statements

It is important that states develop mission statements that clarify the purposes of family placement and recognize the unique needs of children and adults.

The following is a sample Mission Statement based on meetings with state officials and regional office staff in one state.

Sample mission statement

Among the community living arrangements that should be available to people with developmental disabilities is the opportunity to live together with other community members in existing homes in the community. Toward this end, the state office will support opportunities for children and adults to live in typical homes and families in the community.

For *children* with developmental disabilities, the state office's efforts will be directed towards supporting opportunities for children to have a permanent home and a stable relationship with one or more adults. When children cannot live with their natural families or adoptive families, the state office will join with others to provide opportunities for children to live with foster families. In fulfillment of this, the state office will provide support services to children placed in foster care through other agencies; encourage permanency for children placed in foster care; pursue interagency agreements to facilitate the placement of children with developmental disabilities in foster care through other agencies; and, when no other options are available, develop and/or fund options to support children in foster care.

For *adults* with developmental disabilities, the state office's efforts will be directed towards providing opportunities to enjoy close relationships with other people and to participate in home and community life. When justified in terms of individual needs and desires, the state office will join with others to enable adults to live with families or individuals in existing community homes. In fulfillment of this the state office will develop and/or support and fund private agencies to recruit and support community members to open their homes to people with developmental disabilities.

Permanency planning

We recommend that states adopt permanency planning as the official state policy for children with developmental disabilities. In line with permanency planning, each state should periodically review the status of children with developmental disabilities in foster family care and other out-of-home placements with a view towards insuring a permanent home for each through family reunification, adoption, and, if other options are not possible, permanent foster care. Note that social services agencies are mandated to implement permanency planning for all children in foster care placed under their auspices. State mental retardation/developmental disabilities offices should insure that children placed under their auspices receive the same benefits.

Relationships with departments of social services

State mental retardation/developmental disabilities agencies should encourage and provide support services and technical assistance to departments of social services to recruit and supervise foster homes for children with developmental disabilities. As the first course of action in the out-of-home placement of children, state mental retardation/developmental disabilities departments should look to departments of social services. As a matter of policy, no other placement should be considered unless this has been explored and rejected by the department of social services. Support and technical assistance may include: an agreement to provide respite and support services to foster families licensed by the department of social services; consultation on recruitment strategies for families; and practical assistance in individual recruitment efforts.

State mental retardation/developmental disabilities agencies should pursue formal interagency agreements with social services departments to expand foster care opportunities for children with developmental disabilities. State mental retardation/developmental disabilities offices should operate foster care under their own auspices only when no other foster care options are available.

Policies on placement of adults in foster care homes

Policies should provide guidance for the placement of adults in individual family homes. As a general rule, adults should have the opportunity to live in their own homes and placement with an individual or family in an existing community home should be made only when this can be justified on the basis of individual needs and preferences. Placement guidelines should address the situations in which the placement of adults in families or community homes is appropriate:

- the individual expresses a clear choice to live with a family;
- the individual has a preexisting relationship with an individual or family and expresses a desire to live in that home;
- the individual needs companionship and a close personal relationship beyond that which is ordinarily provided by friends and acquaintances;

• the individual has experienced long-term separation from the community and family members and is not likely to form relationships with community members otherwise.

In instances where adults are served in foster care, it is critical that families are supported in viewing the person with a disability as an adult. Training and supports should be tailored to promoting the choices, participation and competencies reflective of an adult.

Provision of individual family support services

Policies should address the provision of support services for families or individuals that accept people into their homes. In order to insure the success of placements, state offices should provide and/or should require agencies to provide flexible family support services based on the individual needs of the family and should allocate funding for this purpose. Support services might include in-home support, home modifications, transportation, out-of-home respite, adaptive equipment and other supports and services.

Funding mechanisms

The rate structure should be based on the actual costs of operating an efficient, effective and responsive family placement program. The funding needs to take into account four major types of costs associated with family placement programs (in addition to medical, therapy and vocational costs).

The *first* major type of cost is *payment to families or individuals*. It is recommended that state offices establish a rate structure based on: (1) room, board and household costs; (2) intensity of services and assistance required by the individual placed in the home. The rate for room, board and household costs could be a standard figure, corresponding to SSI. The rate for services and assistance could vary according to the intensity of support required by the individual. Note that payment for services and assistance would be Medicaid reimbursable.

This rate structure should be used to determine overall budgets, rather than the actual payment to individual families. In other words, agencies should be allowed the flexibility to set payments to families based on local needs and priorities.

In regard to the average rate for both room, board and household costs and services and assistance, $1,000 per month, or roughly $33 per day, is a reasonable figure. With funding from the state's Community Integration program (Medicaid waiver), counties in Wisconsin have successfully recruited families for people with severe disabilities at this level of payment. Similarly, Michigan's Macomb-Oakland Regional Center rate structure is in this range.

The *second* type of cost is for *respite and support services* provided to families. Without adequate support services, many placements, especially for people with challenging needs, are likely to fail. Support services should be individualized and flexible enough to accommodate the full range of needs of families. In terms of budgeting for support services, agencies might be allocated a minimum of $100 per month for each individual placed, with the flexibility to determine the exact amount of funds for support services for any particular family.

The *third* type of cost is for a *personal allowance* for individuals placed in families. Most states and service systems do not provide adequate funding for individuals' personal expenses, such as clothing, entertainment, gifts and so on. As a result, families may be forced to pay for people's personal expenses out of their own funds. Of course, many people placed in homes may be denied basic amenities. A figure of $50 to $100 per month is a minimum figure for a personal allowance.

The *fourth* type of cost is for *agency operating expenses and administration*. Funding for agencies operating programs should be sufficient to cover the costs of recruitment, training, staff (training, recruitment and program specialists and/or case managers), general operating expenses and agency administration.

Conclusion

With increased interest in the foster care "model," it is critical that states and communities begin to examine their existing systems in light of our current knowledge about community living for people with severe disabilities. This article, while not comprehensive, provides an initial step in that examination. For more information on "family care" and community living for people with developmental disabilities, please contact the Center on Human Policy, Syracuse University, 724 Comstock Avenue, Syracuse, NY 13244-4230 or call (315) 423-3851.

This review was prepared with support from the U. S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research under Contract No. 300-85-0076, The Community Integration Project, awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University. The opinions expressed herein do not necessarily reflect the position or the policy of the U.S. Department of Education and no official endorsement by the Department of Education should be inferred.

APPENDIX III

Supporting adults with disabilities in individualized ways in the community

by Julie Ann Racino, Center on Human Policy

This article is based on work on individualized supports conducted by Steve Taylor, Julie Racino, Bonnie Shoultz, Pam Walker, Zana Lutfiyya and Jim Knoll.

During the past few years, the Center on Human Policy has studied a growing number of places throughout the country where adults with disabilities are being supported in individualized ways in the community. When we first began our national search for exemplary practices in community living in 1985, we expected to identify many good examples of group home and apartment living for adults with severe disabilities. We found that the most exemplary practices represented a new way of thinking about providing supports to people with disabilities. Unlike the traditional approach of establishing residential programs, which fit people into the program and then individualized within the context of the program, these agencies were starting with the person first and developing the supports and housing around the person. This article will describe some of the key elements in this new way of thinking about and developing supports for adults.

Key elements in individualized supports

separation of housing and support components

Probably the most critical element in thinking about and implementing individualized supports for adults is the separation of the components of housing and support services. Typically, we have bundled both together, requiring a person to live in a certain place (e.g., a group home) in order to receive a given intensity and type of support (e.g., 24 hour support). By separating the components of housing and support services, it becomes possible for a person (including a person with severe disabilities) to receive supports wherever he or she may live.

This separation of housing and support services can lead to greater control by the consumers:

- **Choice in Housing** - The person can select from a variety of housing choices, depending on his or her particular circumstances—from a duplex to an apartment, a condominium, a flat, a trailer or a house. The person is not required to live in a certain type of housing in order to receive supports. For example, under the supported independence program in Michigan, a variety of housing options (excluding trailers) are available.
- **Choice of Home Location** - The person can choose where he or she wants to live, including the specific neighborhood. Because the housing and supports are not tied together, the person can have greater choice in the home's location. Thus, the location of the home can build on and strengthen natural supports as opposed to severing those ties. As one staff member in Minnesota said, "we help people to decide what neighborhood they will live in and look for a place that seems right for the people."
- **Choice of Living Alone or With Others** - Because the location and number of people is not predetermined, there is greater flexibility in determining how many people will live together. The option of living alone, at least for a period of time, is an important one for some people. Individualized, however, does not mean that a person will always live alone or with one other person. Someone may also choose to live with a number of other people.
- **Choice of Roommates** - The person can have greater choice in his or her roommate(s), if having a roommate or roommates makes sense in his or her life. By separating the aspects of housing and support services, it becomes easier for a person to choose with whom he or she would like to live. Because supports are not tied to a certain setting, one can live with a variety of people (e.g. "typical" people or family members) or alone and still receive the needed intensity of supports. This approach recognizes the critical importance of the people with whom we live and the impact they may have on our lives.

Housing and home ownership

Central among the many critical issues related to housing, is that of leasing and home ownership. People with disabilities are typically required to move to agency-owned housing to receive intense support services. One of the key elements in an individualized approach for adults is the emphasis on a person's living in a place that he or she owns or leases either alone or in conjunction with others. Only in rare instances should an adult live in the home of another or in agency-owned housing.

Ownership and leasing have both legal and personal ramifications. Ownership means that it is the person's home first and foremost. It is a place where staff, rather than the person, can be asked to leave. People with disabilities have seldom had the opportunity for their homes to be their "castles." This approach underscores the importance of "my home" and the feeling of ownership.

Individualized and Flexible Supports

One of the most critical elements in this type of approach to supporting adults is the individualized and flexible nature of the supports.

- **Individualized Supports** - Unlike the typical approach of fitting a person into existing programs, individualization in this situation means tailoring to or developing the supports that will best match the person and his or her current life circumstances. As stated in the Wisconsin Community Integration Program Medicaid Waiver, "Services must be designed or modified to fit the person and meet that person's unique needs." The individualized nature of the supports is typically accomplished through the establishment of an array of possible supports/services that can be accessed by the person—in any combination. For example, individualized supports can include: dental and medical care not otherwise covered; respite; recreation; homemaker services; transportation; attendant care/home health care; therapeutic and nursing services; home and vehicle modifications; home and community training and support; equipment/supplies; legal services; crisis intervention and counseling services and employment services. Since it is impossible to anticipate every type of support that may be needed, it is very important that the array of services includes another category (or some mechanism to insure that unanticipated needs can be met).

Individualized supports have been provided, to some extent, under the home and community based care Medicaid waivers in

a few states. For example, under one state's Medicaid waiver, the following supports can be matched to the individual person and can vary in amount, frequency and duration based on individual needs: respite; homemaker; habilitation (including therapeutic activities; monitoring; supervision; training or assistance in self-care; sensory/motor development; communication; behavioral supports; community living and mobility; health care; leisure and recreation; money management and household chores); adaptive aids and supported employment/day habilitation services. This approach can be more flexibly accomplished through the use of state general funds such as Michigan's supported independence program. Some states combine funding sources (Medicaid, state dollars, county dollars and others) to provide individualized supports.

• Flexible Supports - Flexibility means the supports must be able to be adjusted in a timely way both in kind and in intensity. Thus, supports can be changed over time without the person needing to move from one place to another because "she no longer needs that level of support." When supports and housing are separated, the staff can "withdraw" or "fade" instead of the person needing to move to a new location. This results in continuity for the person and again builds on existing supports. Also, when a person needs more or different supports, he or she can continue living in the same place, but the supports can be changed.

In many ways, this flexibility is much more difficult for service systems to achieve than individualization. We may "individualize" once, but our systems are not often designed to adapt and change at the pace that people change. Flexibility has been built into this approach by keeping decisions as close as possible to the people being supported.

The development of supports

An individualized approach to supports typically involves a change in our way of thinking about "assessment" and "service development."

• Community Assessments - Unlike the typical "deficit-based" assessment, a community assessment involves a less formal process of getting to know the person in a variety of community environments. The emphasis is not on screening in or out of services, but on using the assessment process to determine the supports that will be initially needed. For a good discussion of this type of assessment, see *Getting to Know You: One Approach to Service Assessment and Planning for Individuals with Disabilities* (Brost and Johnson, 1984). More structured ecological strategies (Ford et. al., 1984) can also be used.

Under the Wisconsin Community Integration Program Medicaid Waiver, all assessments must include social relationships, meaningful education or vocational programs, recreation and leisure activities, health and wellness monitoring, social and physical integration in the community, involvement of family and friends, home and protection of individual legal rights.

• Building on Natural Community Supports - An individualized approach to Supporting adults in the community builds on the existing community ties and relationships that each person already has. Instead of supplanting these ties, this approach looks at how these natural supports can be both maintained and strengthened, if that makes sense in the life of the person. Just as Ed Skarnulis (the Minnesota State Director of Human Services) said, "Support, don't supplant the family." it is also important to support neighbors, friends, acquaintances and other relationships in the person's life.

Many of the supports that people with disabilities need are already available through "generic" or community services available to the general public. An individualized approach includes an emphasis on using these existing supports as opposed to the creation of segregated supports and services.

• Changing our Thinking About Supports - This approach requires a shift in how we think about the development of supports and services. In order to facilitate a change in our thinking, a technique called personal futures or lifestyle planning (O'Brien, 1987) has been used to help groups of people create a positive future vision for the life of a specific person with a disability.

This approach is one useful way of beginning to break away from "fitting people into services" and moving toward developing the supports that enable the person to lead a meaningful life. It also asks key questions about what we can do to make this vision occur as opposed to our current focus on what the persons themselves must change.

The way in which we think about supporting people seems to be one of the main impediments to changing to a more individualized approach. While funding mechanisms, regulations and other structures are not always designed to support individualization, often simply shifting our thinking can assist us to recognize options even within current constraints. As one staff member said, "It can be done. It is a problem in thinking."

• Choice of Support Providers - The best examples of supporting individuals included consumer control over the hiring and firing of their staff. In these situations, the staff worked for the person with a disability, not for the agency. The role of the agency was to support the person in managing his or her staff, including the aspects of hiring and firing. As agencies move out of the housing business, their role in the area of support services can also be expected to change. In this area, developmental disabilities services have a tremendous amount to learn from the independent living movement in this country.

Even when people with disabilities do not directly hire or fire their own staff, it is critical that mechanisms be established to provide for staff turnover during the contract period. There are times when a person and his or her support providers will not be a good match, therefore mechanisms to facilitate a change in providers must be in place.

• Availability of Supports for People with Severe Disabilities - Another element that differentiates this approach is the availability of supports. Unlike "supportive apartments" or semi-independent living which typically support people with mild disabilities, this approach enables people with severe disabilities to live in an apartment or home with the supports that they need. For some, 24-hour a day support services are critical. Some agencies we visited were able to discontinue the continual uprooting of people with severe disabilities from their living quarters by helping them to move into their own homes and still maintain the ongoing supports that they required.

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• Increased use of Physical Adaptations - This type of approach also appears to increase the physical adaptations that are made for individuals. When living in one's own place comes first, doing it all on one's own (i.e., process) may become secondary to getting it done (i.e., outcome)...Thus, people can be supported in living meaningful lives before they are able to do it all on their own. We have been continually impressed with the inexpensive innovations that staff, family and the people themselves have developed (e.g., cassette tapes of morning routines strings on cupboard doors) to support people in living intheir own homes.

• Supporting People vs. Independence - A critical issue raised by this approach is the differentiation between helping people to become independent and supporting people in the community. As a reaction to the custodial care of the past, in this decade there has been an increased emphasis on the potential for growth, development and independence of people with mental retardation. While this has been a positive step forward, the interdependence of people has often been overlooked for people with disabilities. A more individualized approach tends to build on existing natural networks of family, friends and associations; provides training and support within the context of home and community and does not require that a person attain certain skills in order to have the right to live in the community and in a home.

Conclusion

This article primarily examined some of the key elements in individualized supports based on learnings from existing programs. Future articles will provide more information on other key elements, such as enabling structures (i.e., funding, training, individual services coordination and other administrative issues) and future directions and issues.

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This article was prepared by the Community Integration Project and the Research and Training Center on Community Integration, Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, with support from the U. S. Department of Education, Office of Special Education and Rehabilitation Services, National Institute on Disability Research and Rehabilitation. No endorsement by the U. S. Department of Education of the opinions expressed herein should be inferred.